

AIDS AND IDENTITY CONSTRUCTION: THE USE OF NARRATIVES OF SELF-
TRANSFORMATION AMONG CLIENTS OF AIDS SERVICE ORGANIZATIONS

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Abstract

The central objective of this paper is to investigate how the experience of living with HIV/AIDS in the U.S. impacts an individual's sense of identity and to what extent this identity is influenced by the institutional ideologies of AIDS service organizations and the "dominant discourse" of AIDS these organizations help produce. My analysis is based upon three years of participant-observation at Gay Men's Health Crisis (GMHC), a major AIDS service organization in New York City, as well as in-depth semi-structured interviews with 34 HIV positive individuals, all of whom are clients of either GMHC or another AIDS-related service agency in New York. In addition, I juxtapose the interview-derived speech data of HIVers with an examination of various kinds of textual material about AIDS – written texts that constitute what I characterize as a "dominant discourse" of AIDS. As my primary unit of analysis, I examine the narratives of self-transformation articulated by interviewees, stories that are quite literally about identity reconstruction. Through these narratives, HIV positive individuals construct their HIV diagnosis as a significant turning point in their lives, interpreting this event as an opportunity to re-fashion themselves into "better" people and to begin their lives anew. Narratives of self-transformation function to rehabilitate HIVers' identities since the new identities many interviewees claim to have achieved after their HIV-impelled journeys of self-reinvention are crafted in accordance with the normative model of HIVer identity established in the dominant discourse.

Chapter 1. Introduction and Literature Review

Introduction

“Faced with...the problem of re-establishing faith in the human order and with the continuing encounter with death, [people with HIV and AIDS] need nothing less than a new identity.”

Robert Jay Lifton, quoted in POZ, April, 1997: 44.

As the quotation above suggests, the experience of living with HIV or AIDS frequently spurs individuals to reevaluate their lives and their own identities. Similarly, the psychologist Steven Schwartzberg states that “[l]iving with HIV is often a voyage into an unknown world, a frightening psychological *terra incognita*”. Yet Schwartzberg also notes an apparent “paradox of the epidemic”: “[a]gainst the bleak backdrop of pain” attendant upon living with the virus and witnessing the devastation it has wrought in many communities, “some folks have developed a capacity to savor life that they previously did not, or could not, know.” (Schwartzberg, 1996: 5) How does this occur? The process by which AIDS is transfigured from a personal and community tragedy into a meaningful, and even uplifting, experience forms the crux of this endeavor.

The overarching goal of this project is to explore the impact of an HIV positive status on individuals’ lives and self-perceptions. A concomitant consideration is the role played by

AIDS service organizations in shaping HIVers' interpretations of the influence of HIV on their lives and identities. More specifically, I employ the methods of cultural and linguistic anthropology, including participant-observation, interviewing and discourse analysis, to illuminate the ways in which HIVers' conceptualizations of self-identity are revealed in and constructed through their interview discourse.

While the impact of HIV on the lived experiences and personal identities of gay white men with HIV has been addressed by previous research in psychology and sociology (c.f. Sandstrom, 1990; Schwartzberg, 1996; Tewksbury, 1994), an objective of this study is to investigate how these experiences compare with those of different groups of people with HIV or AIDS, including women, heterosexuals, people of color and former or current drug users.

This study is based upon three years of participant-observation at Gay Men's Health Crisis (GMHC), a major AIDS service organization in New York City, as well as in-depth semi-structured interviews with 34 HIV positive individuals, all of whom are clients of either GMHC or another AIDS-related service agency in the city. In addition, I juxtapose the interview-derived speech data of HIVers with an examination of various kinds of textual material about AIDS – texts that constitute what I characterize as a “dominant discourse” of AIDS.

The central objective of this research is to better understand how HIVers' identity constructions as "people with HIV or AIDS" are affected by both their participation in the activities and social world provided by AIDS service organizations and by the dominant discourse of AIDS at this particular moment in the history of the AIDS epidemic.

At the time of this writing in 2003, the United States has reached yet another juncture in the history of the AIDS epidemic. On the treatment front, combination drug therapy has improved and extended the lives of many living with HIV disease, yet widespread problems with these drugs, including intolerable side effects, severe toxicities and viral resistance, frustrate the hopes of many HIVers. HIV transmission continues at high rates within low-income communities of color and appears to be ticking upwards within segments of the gay community, particularly among young gay men (*New York Times*, Nov. 27, 2003: A28). Meanwhile, both public funding and private donations to AIDS organizations is decreasing due to a reduced sense of urgency about AIDS; these financial constraints have forced many large AIDS service agencies to cut back their services and many smaller, community-based organizations to shutter their doors. During the summer of 1999, as I was conducting the interviews for this project, GMHC underwent an agency-wide "restructuring" impelled by a steep decrease in their annual funding, just as the New York City branch of the People With AIDS Coalition's nationwide network of "peer-based" organizations was bought out by a competing city AIDS agency, ultimately folding altogether a few months later. At the same time, certain

voices within the gay community are calling for the creation of “post-AIDS identities and cultures”, asserting that “the event of AIDS as epicenter gay men came to know it in the 1980’s is over.” (Rofes, 1998: 14). In light of these new and continuing developments, an understanding of the lives and experiences of HIVers from a variety of social backgrounds is especially apposite; emerging from a specific historical point in the AIDS epidemic in the U.S., this work is mindful of the ways in which continuing social, medical and institutional changes are impacting the lives of HIVers.

The Dominant Discourse of AIDS

A central claim of this work is that AIDS service organizations (ASOs) such as GMHC contribute to a broad-based “dominant discourse” of AIDS, a discourse that represents the “science of HIV/AIDS” and whose fundamental tenets are shared by the medical and public health establishments in this country. This “dominant discourse” consists of a variety of textual formats, including interactional and written texts alike, that are simultaneously produced in multiple institutional locations within the “AIDS system” of organizations. ASOs, which comprise a key institutional component of the “AIDS system”, are important contributors to this dominant AIDS discourse in two capacities. These agencies produce texts – ranging from HIV treatment newsletters and self-care pamphlets for HIV positive clients to position statements on local and national AIDS policy issues – that convey the key themes of the dominant discourse. Further, through

the direct services they provide, ASOs function to inculcate clients in the normative ideology that forms the substrate of this dominant discourse.

This normative ideology, in turn, impacts the identity constructions of HIV positive individuals. As I will demonstrate, the dominant discourse establishes an image of the “good” or “proper” person with HIV/AIDS which HIVers, especially those who are active clients of AIDS service agencies, must grapple with and position themselves in relation to. This model of HIVer identity prescribes particular behaviors and forms of subjectivity as normative, or “preferred”, for HIVers. Most saliently, the dominant discourse conveys a preferred stance towards one’s HIV status, communicating to HIVers first, that their HIV status is a fundamental component of their personal identity, and second, the particular ways in which they should construct their identities around HIV.

Thus, it is my contention that the dominant discourse of AIDS significantly shapes HIVers understanding of themselves, their pasts and their futures. As the words of interviewees will reveal, HIV positive individuals both interpret their lives and identities, and construct their discursive self-presentations, in light of this normative model. The narratives of self-transformation in which interviewees use their HIV positive diagnosis as a pivot for the invention of a “new and improved” persona represent one such discursive self-presentation.

Narratives of Self-Transformation

The defining thematic element of interviewees' narratives of self-transformation is the presentation of HIV as a catalyst for major life change. In this discursive form, interviewees present their life stories as marked by a narrative disjuncture; the event of their HIV diagnosis precipitates a crisis of identity which is resolved by their eventual acceptance of this diagnosis and the new reality it brings. In addition, the process of coming to terms with one's HIV diagnosis is interpreted by narrators as a turning point for the construction of a new self-concept. For these individuals, the experience of living with HIV effects a transformation in both their daily lives and in their identities; just as their diagnosis shapes the activities they engage in, the nature of their significant relationships and their overall quality of life, it also alters their perception of themselves, and what gives meaning to their lives. In this manner, narratives of self-transformation function to rework an involuntary crisis into an opportunity for self-growth. Significantly, the rebirth that is brought on by HIV diagnosis allows for the creation of new lives and identities that are interpreted by narrators as changes for the better.

The use of narratives of self-transformation is the dominant pattern within my sample of interviewees; 21 of the total number of 34 interviewees within the sample use this discursive form. Moreover, the use of these narratives cuts across distinct demographic groups. Represented within the subgroup of interviewees who articulate this discursive form are a number of gay men, including both white gay men and gay men of color, as

well as a significant proportion of heterosexual women and men, including Latino/as, African-Americans and whites.

My overall analysis of interviewees' narratives of self-transformation examines both the content of these narratives as well as certain structural aspects of interviewees' discourse with an eye towards the intertextual relations that obtain between HIVers' language use and the texts of the dominant discourse. By attending to the multiple parallels between the dominant discourse's image of the "proper HIVer" and the new identities many interviewees claim to have achieved after their HIV-impelled journeys of self-transformation, I hope to highlight the discursive functions of these narratives for HIVers. I argue that narratives of self-transformation serve to rehabilitate HIVers' identities by presenting an individual as having undergone a personal transformation subsequent to his HIV diagnosis that brings his identity in line with the normative model. Thus, for many narrators, these narratives function as a way of compensating for life histories and pre-HIV identities that are heavily stigmatized within both mainstream U.S. culture and the dominant discourse of HIV/AIDS. The dominant discourse of AIDS makes such a transformation *possible* by creating an idealized vision of the "proper" or "good" person with HIV/AIDS that individual HIVers may measure themselves against and strive to conform to. And it makes such a transformation appear *necessary* by cloaking this image in moral rhetoric, so that an HIVer who chooses to flout these norms does so at the peril of her identity as a "good" and moral person.

In the next section of this chapter, I turn to a brief overview of academic literature relevant to my analysis, paying particular attention to the connections between my analysis and recent theoretical currents within linguistic anthropology. In Chapter 2, I outline the methodologies by which I collected the data for this study, and provide a sketch of the demographic characteristics of my overall sample of 34 interviewees. Chapter 2 concludes with a discussion of the ethnographic context of this study – that is, the “AIDS system” of institutions in general and the AIDS service organization GMHC in particular.

The first section of Chapter 3 is largely theoretical, presenting my conceptualization of the “dominant discourse” of AIDS; this is followed by a discussion, based on an explication of textual examples, of the central themes and ideological assumptions of the dominant discourse. Chapter 4 is devoted to an in-depth exploration of the narratives of self-transformation articulated by interviewees, attending to the thematic content of these narratives, the structure of interviewees’ language use on the lexical and phrasal level, and a comparison of interviewees’ speech with texts of the dominant discourse. Finally, in Chapter 5, I offer a critical evaluation of these narratives of self-transformation, considering the potential implications of their use for HIV positive individuals.

Literature Review

Introduction

This section covers two main areas of academic literature that inform my analysis. The first is literature that takes language as its primary analytic focus and source of data, chiefly from linguistic anthropology and related fields; the second is literature from a variety of disciplines within the social sciences and humanities that is specifically concerned with the topic of HIV/AIDS.

While the present research is fundamentally anthropological in its attention to the sociohistorical context of HIVers identity constructions, the methods and perspectives of anthropology serve as broad framing for interdisciplinary influences. My approach to understanding HIVers' identity constructions in narratives of self-transformation is grounded in the sociological traditions of symbolic interactionism (c.f. Goffman, 1959 and 1963) and ethnomethodology (c.f. Garfinkel, 1967). Goffman's and Garfinkel's work reveals how social identities are established and managed in routines of face-to-face interaction, behavior in which language use is central. The sociolinguistic school of conversation analysis has built upon this work, offering a rigorous methodology for studying the process of face-to-face interaction with the significant advantage of revealing how identities emerge over successive "turns at talk" (Sacks, Schegloff and Jefferson, 1974). However, conversation analysis in general can be faulted for neglecting

the significance of the larger social and interactional contexts within which conversation is produced. Anthropological work has contributed to this sociolinguistic tradition by emphasizing both the contextually situated nature of speech and the diversity in forms, or genres, of language use.

Within linguistic anthropology, my work is indebted to the theoretical insights offered by several strands of literature representing distinct topical foci within the discipline.

Ideology

First, my research is influenced by examinations of the role of language in the constitution and reproduction of sociocultural ideologies, especially dominant ideologies (c.f. Philips, 1998; Whisman, 1996); a focus on ideology is useful as it enables a linkage of linguistic analysis with a consideration of forces of power within society.

Two aspects of ideology are crucial my analysis. First, ideology is intimately bound up with power. Necessarily selective, ideology represents the interests of the few over the many, in service to the dominant elements of society. Second, ideology is covert; its alignment with powerful groups whose interests it serves is concealed as it purports to universality. As a direct consequence of its covert nature and universalizing tendency, ideology functions to legitimize the status quo. Because ideology serves the interests of power while keeping its vested nature covert by means of a universalizing pretense, existing social relations of domination and subordination are made to seem “natural” and thus pre-ordained. From this perspective, inasmuch as the dominant discourse of AIDS serves to maintain the status quo and attenuate critique of an existing social order, it can be understood to be “ideological”.

An emerging body of work within linguistic anthropology concerns “language ideologies”, investigating the processes by which ideologies about entire languages or about particular forms of language use contribute to the formation of sociocultural

institutions such as the nation-state or ethnic identity (c.f. Gal and Woolard, eds, 2001; Kroskrity, ed., 2000). While the present research is influenced by this literature's use of the concept of "ideology" as a way of infusing an analysis of the intersections between language and culture with an attention to power, my topical focus is distinct. My concern is not with ideologies *about* language, but with ideologies of identity that are expressed *through* language – specifically, the ways in which the dominant discourse of AIDS, as constructed in texts produced by institutions such as ASOs and the mainstream media, conveys ideological notions of how to be a "proper" HIVer and how to live a "good" and "meaningful" life with HIV. Despite this difference, the present study shares with this literature an attention to the role of ideology in the constitution of social norms, or behavioral standards and standards of value; as I will demonstrate, the ideology of the dominant discourse creates a hierarchy of identities according to which certain orientations to one's HIV status are more positively valued than others.

Identity

In the past two decades, new approaches to identity of relevance to my work have emerged within the humanities, most saliently, within cultural studies and queer theory. Recent work in this area has explored the influences of race, class, gender and sexuality on identity (c.f. Anzaldúa, 1987; Sedgwick, 1990). In terms of its theoretical orientation, this literature is dominated by a constructionist stance that conceives of identity as embedded within and produced by larger cultural relations of power. In the 1990's, this interdisciplinary work on identity has become manifest in anthropological studies (c.f. Behar, 1993; Kondo, 1990) that apply similar theoretical understandings to cross-cultural settings while stressing the importance of historical and cross-cultural influences on identity formation.

My project is deeply influenced by the theoretical insights of this body of work, particularly its centralization of the ways in which structures of power impact processes of identity formation and individuals' subjective experiences of the self. Ethnographies such as Kondo (1990), which explore the emergence of new subjectivities within capitalist socioeconomic contexts, provide cultural anthropological models for my own focus on HIVers' negotiation of identity.

Especially relevant to the present analysis is the body of literature within sociolinguistics and linguistic anthropology on the role of institutions in language-based processes of

identity construction. Focusing on language use within institutional contexts is useful as it offers a way to connect a concern with identity with an attention to ideology. Thus, by examining the ways in which institutionally-produced language functions to both constitute dominant ideology and shape individuals' subjectivities, I attempt in this study to bring an interrogation of power relations to bear on forms of personhood.

The examination of verbal interactions in medical bureaucratic encounters is an outgrowth of the conversation analysis school of sociolinguistics. (c.f. Dew and Heritage, eds. 1992) Such studies indicate that clients' needs are typically suppressed within routinized and inflexible interactional processes, such as intake interviews (c.f. Heller and Freeman, 1987). While this literature offers a useful understanding of the distinctive organization of talk that is characteristic of bureaucratic contexts, it can be faulted for a narrow focus on conversational structure that devotes relatively little attention to the content of these verbal exchanges, the interaction between form and content of speech and the larger cultural relations of power within which this speech is embedded.

More recent studies within linguistic anthropology proper by Meacham (2001), Mehan (1996) and Houghton (1995) offer a corrective to this decontextualizing tendency. These studies all enrich an attention to microinteractional detail that is typical of CA work on bureaucratic language use with a rich understanding of the institutional setting, as well as the larger sociocultural context within which the speech they examine is embedded. Moreover, they also display a greater degree of theoretical sophistication with regard to

recent conceptualizations of identity and power. For example, in her analysis of the “rehabilitative practices” of a “court school” for juvenile offenders in L.A., Meacham illustrates how institutions exert their authority not through physical coercion, but through their authority to define and interpret behaviors. By “reading” students’ behaviors, attitudes, bodily postures and affective portrayals, teachers at the school construct students’ identities in terms of the dominant local moral economy of “street vs. school”; this broad interpretive framework is applied by teachers’ to discrete student self-presentations so that students’ relative rehabilitative progress is measured in terms of shifting allegiance from “street” to “school”.

My work is distinct within this tradition as it focuses on a different “identity” than is customarily examined within linguistic anthropology; it is my claim that “HIV positive” functions as an identity category in much the same way that anthropologists and others have conceptualized the identities of gender, race, class and sexual orientation. As I will detail, the identity of a person “living with HIV or AIDS” is both constructed in articulation with dominant ideology – as represented by the dominant discourse’s normative image of the “proper” HIVer – and contextually situated, emerging from the local context of the AIDS service organization as well as the broader cultural context of the U.S. at the turn of the millenium.

Narrative

Recent work within anthropology, sociolinguistics and the humanities more generally has come to privilege narrative as a site of identity formation (c.f. Hill, n.d.; Miller, Potts, et al, 1990; Ochs and Capps; 1996). Certain researchers, including some anthropologists, favor an exclusively content-based approach to the use and analysis of narrative data (c.f. Behar, 1993; Whisman, 1996), while other work, particularly the narrative analysis of sociolinguists such as Schiffrin (1996) and Goodwin (1990), is more empirically grounded in the tradition of early conversation analysis. My aim in the present research has been to inform a content-based analysis of interviewees' narratives of self-transformation with an attention to certain elements of sentence-level language structure – specifically, lexical items and conventionalized phrases – by which these narratives – and HIVers' identities – are constructed.

Traditionally, many researchers in sociolinguistics, linguistic anthropology and related fields have conceptualized “narrative” as a bounded discursive unit of spoken or written language. This notion has roots in the Labovian variationist tradition (Labov, 1972), as well as linguistic anthropology's traditional focus on oral narratives as verbal art (c.f. Bauman, 1986; Urban, 1991).

In contrast, some recent work deploys a looser conceptualization of “narrative” that is defined less by its formal structural features than by its discursive function. In

Mattingly's examination of the new life stories co-constructed by victims of severe spinal cord injuries and their occupational therapists within the institutional setting of a rehabilitation facility (Mattingly, 1998), a "narrative" is not necessarily a discrete unit of discourse containing predictable sequential components such as an "evaluation", but a "story" in which dramatic tension is the central, defining feature. It is this sense of "narrative" that is most applicable to the stories of self-transformation articulated by the HIV positive interviewees in the present study, stories that are defined primarily by their thematic content and ideological assumptions.

Furthermore, while many researchers, such as Linde (1993) and Polanyi (1985), have focused on the role of life stories in creating a "coherent" story line from the chaos of experience, Mattingly points to the limitations of this emphasis on the "coherence"-building function of narrative, arguing in favor of the importance of "drama" in individuals' life stories – a theory that accords centrality to desire, as opposed to linearity. Mattingly highlights the role of narrative in structuring lived experience; the function of narrative, she asserts, is not merely to provide a *post hoc* rendering of experience already lived, but to guide and shape experience not yet lived. Thus, Mattingly's view of narrative is more forward-directed inasmuch as she sees narrative as a *form* of social action, not epiphenomenal to it.

Both Whisman (1996) and Mattingly address the nature of the relationship between narrative and lived experience, an issue that is a point of debate within narrative theory,

arguing against a strict causal connection between narrated events and narrative content or form. Whisman points to the insufficiency of such an explanation by showing how individuals with similar sexual histories can articulate divergent “accounts” of sexual identity formation, while Mattingly emphasizes the role of desire in structuring both narrative and experience, claiming that our projected image of ourselves in some desired future state of being shapes our actual experience of events on the ground. This bears on my work inasmuch as HIVers’ life events alone, as will become apparent, are not sufficient to explain their use of narratives of self-transformation.

Whisman’s and Mattingly’s insights challenge traditional analyses, represented by Linde and Polanyi, that treat narratives as direct and transparent reflections of lived events; instead, they insist, narratives are *interpretations* of experience, profoundly shaped by a multitude of contextual factors – from the political ideology of the narrator (Whisman), to the contributions of a co-narrator, which are themselves shaped by that individuals’ own motives, moods, and miscues (Mattingly).

Mattingly argues for the importance of desire in shaping narrative plot; a central function of personal narratives, she claims, is to help us envision a future for ourselves, to project our identities into a desired future state. While her claims are borne out by my data, I would shift the emphasis of her argument slightly. As interviewees’ narratives of self-transformation make clear, in articulating personal narratives individuals do not just write themselves a future, but also, or perhaps more so, they re-inscribe their pasts, continually

re-interpreting the past to accord with their present sense of self. As our sense of identity shifts according to multiple elements of context (encompassing everything from our advancing age and to our ever-accruing experience of life to elements of context such as the identity of our interlocutors and so forth), so too does their understanding and their telling of their personal history.

These theoretical claims relate to narratives of self-transformation because it is through these biographical stories, and their attendant interpretation of past events, that HIV positive individuals attempt to re-create a more favorable identity for themselves and for society – an identity that is socially sanctioned within the “AIDS system” of institutions and repeatedly presented and reinforced within the dominant discourse of AIDS.

Literature on AIDS

Many of the theoretical and methodological issues discussed above apply to humanities and social scientific research on HIV/AIDS. A significant body of literature on HIV/AIDS issues has emerged from the interdisciplinary field of cultural studies. Typically, this work has engaged in cultural critique of dominant discourses about AIDS in the popular media and in the medical/scientific establishments.(c.f. Kruger, 1996; Martin, 1994; Treichler, 1999; Waldby, 1996) For instance, Waldby argues that biomedical AIDS discourse, and by extension, popular knowledge of AIDS, pathologizes the identities of gay men and heterosexual women by equating these entire groups of people with “unhealthy” sexuality. While work in this area displays a high degree of theoretical sophistication, it perpetuates hegemonic discourses inasmuch as the subjective experiences of people with HIV/AIDS are subordinated to the project of deconstructing dominant ideologies. An exclusively textual focus backgrounds the actual voices of those living with HIV/AIDS. Furthermore, the majority of this work has focused primarily upon hegemonic portrayals of gay men, while the dominant meanings ascribed to other groups of people deeply affected by AIDS, such as former and current drug users, have been less represented.

In contrast, medical and cultural anthropologists have addressed social issues surrounding AIDS by conducting ethnographic research within specific communities; much of this research is cross-culturally based. (c.f. Manalansan, 1995; Parker, 1992) By illuminating

how certain culturally specific behaviors, such as heterosexually-identified Latino men having sex with other men, are elided by a mainstream public health focus on homogenized “risk groups” of gay or bisexual men, the anthropological contribution to AIDS research has demonstrated the utility of qualitative research methods that are the most effective way of understanding local categories of meaning and behavior within their cultural contexts.

However, anthropological studies of HIV/AIDS have predominately been concerned with gaining emic perspectives on HIV transmission behaviors, with the goal of designing more effective prevention strategies (c.f. Connors and McGrath, 1997). There is a need for more anthropological research on the subjective experiences of people *living* with HIV at home, in the workplace and in their communities, as well as comparative data examining how these experiences are influenced by differences in social context.

The most prominent research on HIV/AIDS and identity has emerged from the fields of sociology and psychology (c.f. Adam and Sears, 1996; Klitzman, 1997; Schwartzberg, 1996; Tewksbury, 1994). Tewksbury has investigated, through the implementation of interview methodology, HIVers’ management of “spoiled identities”. While providing an illuminating application of Goffman’s theory of symbolic interactionism, this study is not driven by a concern for language beyond the use of lexical items, or identity “labels”, by which HIVers refer to themselves. On the whole, the sociological and psychological literature on AIDS and identity is characterized by both a strictly content-based approach

to the analysis of interview data, as well as a prioritization of the identity issue of gay white men with HIV.

There is very little existing work on HIV/AIDS with an explicitly sociolinguistic or linguistic anthropological focus; I am aware of only two monographs, Perakyla's *AIDS Counselling: Institutional Interaction and Clinical Practice* (1995) and Silverman's *Discourses of Counselling: HIV Counselling as Social Interaction* (1997), both of which are micro-interactional studies emerging from the CA tradition of face-to-face verbal interactions within bureaucratic settings. Neither Perakyla nor Silverman primarily focuses on the lived experiences and language use of people with HIV/AIDS; instead, both centralize dyadic clinical interactions between counselors and clients.

In sum, my approach to understanding HIVers' identity constructions is distinctive within this literature on HIV/AIDS inasmuch as it aims to combine an analysis of two forms of language – textual data of the dominant discourse and HIVers' interview-based language use – with an understanding of the broader sociohistorical context gained through extended ethnography. This work hopes to bring the textual analysis of cultural studies work on HIV/AIDS to bear on HIVers' actual language use with the purpose of elucidating the effects of hegemonic AIDS discourse on ASO clients' identity constructions and self-presentations.

This research also has the potential to enrich the formalistic approach to the study of everyday speech that is characteristic of much discourse analytical work with an attention to the wider cultural context, particularly the institutional context of the AIDS system, that is informed by long-term participant-observation. At the same time, it promises to contribute to the burgeoning interest in identity formation within cultural and linguistic anthropology, and the humanities more generally, by providing empirical documentation of HIVers' identity constructions in language. Finally, basic research on HIVers' experiences within AIDS service organizations may contribute to practical applications, as specific documentation of the lived reality of diverse groups of HIVers is a first step towards improving AIDS services.

Chapter 2. Methodology & Sample Description

Research Methodology

In this research, I have aimed for an integrative approach, combining ethnographic participant-observation conducted in the institutional setting of an AIDS service organization (ASO) with an analysis of the tape-recorded speech of HIV positive individuals derived from the interview context. Specifically, this study is based upon three years of ethnography at Gay Men's Health Crisis (GMHC), a large AIDS service organization in New York City, as well as in-depth semi-structured interviews with 34 HIV positive ASO clients. In addition, I juxtapose interviewees' speech with various forms of entextualized language about AIDS produced by institutions of the "AIDS system".

The component of participant-observation is vital to the study's overarching theoretical orientation; this methodology prioritizes the lived experience of individuals, and has the ability to provide rich documentation of the various means by which people construct meaningful identities. My discourse analytic methodology is explicitly concerned with the analysis of everyday speech and the relationship between this speech and broader cultural ideologies. Such a methodology has the potential to reveal the specific mechanisms by which people continually construct, negotiate and present their self-conceptualizations in articulation with a larger sociocultural context.

For both pragmatic and theoretical reasons, the methods I employ are varied, complementary and “intertextual”. As I will discuss, because of difficulties I encountered in implementing my original methodological goals, I have adopted an “intertextual” approach. The purpose of this approach is to gather evidence of individual HIVers’ and institutional interpretive perspectives and ideological stances by utilizing distinct forms of language as data, including both oral and entextualized language and various “genres” of language.

Another goal of this research is to compare the experiences of a diversity of HIVers. To that end, I have included a wide cross-section of HIVers in my sample of interviewees in an effort to understand how experiences of HIV are inflected by differences of race/ethnicity, class, gender, sexual orientation and other factors.

A Problem of Access

In conducting this research I faced several significant methodological challenges. These challenges included: how to gain entry into the institutional setting of an AIDS service organization, my intended “field site”; how to solicit interviews from clients and staff members of the organization and how to gain staff members’ interest and cooperation in assisting my recruiting efforts; and how to gather “socially-occurring” speech within this institutional context, an issue that was exacerbated by confidentiality concerns and regulations surrounding HIV/AIDS. As I discovered, the challenges I faced were largely the result of two factors – the topical focus of my research, namely HIV/AIDS, and the institutional context of the AIDS service organization where it was conducted.

It goes without saying that AIDS is a sensitive issue in the contemporary U.S. An individual’s HIV status is personal information of the most intimate kind; due to the continuing stigma attached to an HIV positive serostatus, it is socially “dangerous” information that has the potential to “spoil” one’s. Understandably, then, this knowledge is carefully guarded by HIVers and officials of the AIDS institutional system alike. Indeed, as the HIV positive individuals I interviewed for this study made clear, the issue of “disclosure” is significant for many HIVers, and a wrenching emotional dilemma for some. In certain communities of HIVers, especially among gay men in New York City and elsewhere where HIV infection has become all too common an occurrence, social norms and ethical precepts have been formulated to guide disclosure, governing, for

example, the particular interactional contexts in which one is morally obligated to divulge one's HIV status. AIDS service organizations, including GMHC, even offer workshops on "disclosure" to help individuals negotiate this often rough social terrain.

In light of the sensitivity of an individual's HIV status as social information, and in the face of the massive stigmatization and discrimination directed towards HIVers in the early years of the epidemic in this country, the U.S. crafted strict confidentiality protections around AIDS that do not exist for other diseases. These regulations – which operationalize a philosophy known as "AIDS exceptionalism" – have significantly influenced the present study. As I will explain, my research methodology was shaped in direct response to the kinds of interactional contexts I could and could not gain access to.

In addition, the institutional site of my research, specifically, the service organization context, created its own particular challenges. A major issue facing those who wish to conduct research within service organizations in general is how to gain the cooperation, and avoid overburdening or engendering the hostility of, frontline staff members who are typically those whose cooperation is most needed as they interact with clients on a routine basis. As I have learned in the course of other research within treatment and service organizations, problems can arise if staff members' sole experience with social scientific research consists of having been the object of evaluation research; if agency workers conflate all interview-based research, say, with evaluation research, their fear of being judged may contribute to a disinclination to cooperate with a researcher. Another

problem, one that can potentially extend to the highest levels of organizational management, is “what’s in it for me?”, or the issue of what fruits of the research accrue to the organization’s staff and management in return for their expenditure of time and effort.

Another factor that may have influenced the course of my research is my own status as student, as well as my dearth of professional connections to “insiders” within the field of AIDS services research. On the one hand, because I am a student, and thus fairly low on the academic prestige scale, with little to offer service organizations in the way of recompense, it was extremely difficult for me to capture the attention of senior management at many of the organizations I approached. On the other hand, it is also possible that my relative lack of status contributed to my success in gaining the cooperation of GMHC staff inasmuch as my identity as a student made me less threatening. Moreover, since I was an “outsider” to both the AIDS service industry and the social services field in general, the management of GMHC may have felt that cooperating with me would be unlikely to have negative ramifications for the agency.

Balancing the challenges, several factors particular to GMHC at the time of my research in 1997 through 2000 facilitated my efforts to gain the cooperation of GMHC officials. For example, the woman who had newly been appointed to the position of Executive Director when I sought approval from the agency, Ana Oliveira, is herself a medical anthropologist; she was, therefore, more favorably disposed to the aims and methods of my research than she might otherwise have been. In addition, since GMHC is the largest

and most prominent ASO both within New York City and nationally, with a history in the AIDS field that dates back to the earliest years of the epidemic, the agency is more accustomed and amenable to fielding requests from researchers who want to solicit the participation of their staff and clients than are some of the smaller community-based organizations I approached. In fact, a few years prior to my research, before a series of financially-motivated cutbacks, GMHC had an internal research department which conducted needs-assessment research among the agency's clients, as well as evaluation research to assess the efficacy of the organization's programs and services. To the extent both of these factors functioned to familiarize frontline staff members such as casemanagers with the presence of researchers in their workplace, this may have helped me gain their cooperation – cooperation that was essential in publicizing my study among the agency's clientele.

However, the most significant factor that enabled me to gain access to socially-occurring activities at GMHC was my decision to join the agency as a volunteer. In October of 1997, I participated in two rounds of training at GMHC, first the general training required of all volunteers, followed, some months later in 1998, by the more intensive four-day training specifically geared to volunteers who want to work in the agency's Buddy Program. For the next three years, I participated in a wide variety of GMHC activities as a volunteer – from regular meetings with the individual client, a heterosexual African-American man living in Brooklyn, for whom I became a Buddy, to agency-wide public forums and lectures on a panoply of HIV-related issues, to strategy sessions and lobbying

visits to New York State legislators in Albany with New York Citizens' AIDS Network, the grassroots advocacy project administered through GMHC's Public Policy department. While I made my research interests and intents known to the staff members and clients with whom I regularly interacted, I limited my involvement to these volunteer activities for two full years before approaching agency officials about beginning formal data collection procedures; thus, by the time I solicited their approval of my study, I had become a familiar face at the agency who was known by staff members in several departments.

In the intervening time, I rethought my overall methodological strategy with a better idea of the kinds of data it would be possible for me to collect. Ultimately, I was forced to relinquish my original plan to tape-record speech data from interactions between GMHC staff members and clients, as the confidentiality protections for people with HIV, particularly in the context of a service institution, severely limited my access to these interactional contexts. In response, as I looked for new sources of language data to instantiate the overarching ideological principles of the service institution, I began collecting a wide variety of textual material produced and/or distributed by GMHC, including flyers advertising agency services such as support groups and medication adherence workshops; pamphlets and magazines offering primers on new advances in the medical treatment of HIV; action plans and "talking points" about AIDS-related public policy issues distributed at NYCAN meetings; and literature on counseling techniques,

harm reduction and other models from the drug abuse, mental health and HIV treatment and services fields that were used in volunteer training sessions.

Because I was unable to collect the kinds of “socially-occurring” speech that I had initially envisioned as a major source of data, these textual materials, along with the one-on-one interviews with HIV positive individuals, became my two primary sources of language data. As a supplement to this speech data, I have also relied on the fieldnotes I took during the three years I volunteered and conducted participant-observation at GMHC.

Interview Data

With regard to the interview-based speech data, in total I conducted one-on-one, semi-structured, tape-recorded interviews with 38 HIV positive individuals, all of whom were clients of either GMHC or another city AIDS service organization. However, the first four interviews I conducted are not included within my final sample, as they were “pilot interviews” designed to help me refine my list of questions.

Interviewees were recruited primarily by means of flyers advertising my study which GMHC staff members posted in various locations at the organization’s headquarters in Manhattan’s Chelsea neighborhood. Several interviewees were also referred through word-of-mouth from their casemanagers or other GMHC staff members. In order to ensure that an adequate number of women would be represented in my sample, I sought the assistance of the Director of the Women’s Services division who was very helpful in encouraging her staff members to recruit female clients into the study.

Twenty-nine of the final sample of 34 interviewees were active GMHC clients at the time of their interviews. Three of these 29 GMHC clients, all gay men, were also employed as part-time “peer health specialists” at GMHC when they participated in the study. The five interviewees who were not GMHC clients were referred to the study through “snowball sampling” – typically through a friend or acquaintance of the interviewee’s who was a GMHC client and had seen my flyer posted at the agency.

Interviews ranged in length from approximately forty-five minutes to three hours, with the majority 60 to 90 minutes long. All interviews were conducted in a small private room at GMHC, with the exception of two men whom I interviewed in their rooms at Solutionz, a Brooklyn-based SRO-style residence and social service agency for homeless HIVers. In the years following my ethnographic research at GMHC, the 34 interviews included in my final sample were transcribed with the assistance of a paid transcriber. A complete inventory of these 34 interviewees, including each individual's pseudonym and interview date, along with his or her gender, age, race/ethnicity and sexual orientation, is included in Appendix A.

Participants were compensated, at the rate of \$10.00 per hour, for interview time. It is possible that this strategy affected the speech data collected. Since they were paid by the hour, interviewees may have been encouraged to extend their narratives more than they would in "ordinary" situations. Also, it is possible that the financial benefit, however small, encouraged the participation of HIVers who were particularly poor. Nevertheless, the ethical necessity of compensating interviewees, the majority of whom were living on fixed incomes from disability benefits or public assistance, I believe outweighed these empirical concerns.

The one-on-one semi-structured interviews with ASO clients provided a formalized means for eliciting the narrative speech data that is analyzed in Chapters 4 and 5. During

these interviews, I talked with HIVers about their lives both on a personal level as well as in relation to their interaction with and involvement in institutional structures and community-based organizations. We discussed how they managed their illness on a variety of levels – how they received treatment and benefits; whether they were working or had worked in the past; how they dealt with disclosure and discrimination; what goals they had in life and what “kept them going”; and “what a typical day is like” for them. A copy of the complete interview schedule used for these interviews is included in Appendix B.

Following the model established by Kennedy and Davis in their oral history of the working-class bar-based lesbian community in pre-1970 Buffalo (1993), these interviews were designed to be flexible and open-ended, so that the interviewees and I could address locally salient issues. My opening question “Can you tell me a little bit about yourself or describe yourself to me?” was intended to initiate talk without over-determining its content, giving the respondent an opportunity to define both the structure and content of the interview. While I used the interview schedule as a guide for the key topics or domains to be covered, the order in which these topics were addressed, as well as the order and wording of the questions I asked about each topic, was adaptable to the discourse of the interviewee. I strove for consistency in topics covered while allowing for flexibility. Wherever possible, I let respondents take the lead in initiating topics and determining the overall flow of talk.

I also made use of a strategy for eliciting specifically narrative data that is inspired by the Labovian model of the sociolinguistic interview (Labov, 1984). This strategy consisted of a nested structure of questions in which broad questions about a specific topic were followed by a probe such as “Have you ever had a particular experience that summed up these feelings for you?” that is designed to elicit a narrative response. In fact, many of the interviewees who articulated narratives of self-transformation did so spontaneously, with little or no prompting from me.

In defense of the utility of interview speech as language data, I point to the fact that the interview is a socially occurring genre of speech in mainstream U.S. culture, one that is particularly common in institutional life. Therefore, all the interviewees in this study had at least some prior experience with interviews. At the very least, most of them had taken part in the intake interview required of all new GMHC clients; many had also taken part in other AIDS-related research projects, whether clinical trials or social scientific research. Apart from their familiarity with the interview genre, in telling the stories of their lives interviewees could analogize the interview situation with more familiar interactional contexts in which they would tell personal stories, such as casual conversation, using this interactive framework as a model for their behavior.

Furthermore, it can be argued that, even in relatively unfamiliar contexts, people are likely to deploy familiar interpretive repertoires and routinized strategies of self-presentation, as they draw on the knowledge and behaviors they have at their disposal. Finally, I point to the fact that my interpretations of HIVers’ interview speech are

informed by understandings gained through participant-observation in a variety of interactional contexts and activities.

In addition to these one-on-one interviews, I also conducted less formal interviews with several staff members of GMHC, including the Director of the Women's Services division, two longtime GMHC casemanagers and the "peer" facilitator of a weekly Parenting Workshop I attended. All of these interviews, with the exception of the one with the Director of Women's Services, were tape-recorded and later transcribed. Although these interviews are not included within my final sample of interviewees or quoted in the text that follows, they have helped me to understand the broader institutional context of ASO clients' language use.

I would like to conclude by highlighting what, in retrospect, might be viewed as an unexpected benefit of the exigencies of my particular "field site". The difficulties I encountered gaining access to socially-occurring speech led me to introduce textual data into my research design, an adaptation that drew me to the intertextual analysis deployed here. This analytical format, in turn, enabled me to make connections between clients' discourse, on the one hand, and the institutional discourse of the ASO and the broader "dominant discourse" of AIDS, on the other hand. Such an analysis provides, I believe, a means for illuminating certain processes by which dominant ideologies are produced, reproduced, disseminated and internalized – in other words, to show how hegemony happens. This experience serves to underscore the value of the anthropological method;

ethnography, inherently flexible, allows for an adaptation of a research design in response to the particularities of the social context in which the research is conducted. Indeed, had I set out with a predetermined and rigid methodological format, I may very well have been unable to proceed with the research. Although I ended up with a somewhat different project than I had planned, the access problems I experienced ultimately compelled me to rethink the ways in which I had intended to use language data.

More broadly, it can be said that the use of interview data is not currently in vogue in linguistic anthropology and sociolinguistics today; instead, a reliance on “socially-occurring” speech, particularly face-to-face communicative exchanges, is more common – especially among discourse analysts working within the social context of the contemporary U.S. (c.f. Ochs and Taylor, 1995; Schiffrin, 1996; Tannen, 1986) In fact, the influence of CA-inspired methodologies and the interactional school of sociolinguistics has now reached far beyond the disciplinary boundaries of anthropology and linguistics. While I level no criticism at this methodology *per se*, I do believe there is room for work that looks at other forms of language. For example, as mentioned in the previous chapter, the existing interactionally-based literature on language use in institutional settings is fairly limited; lacking contextual insights derived from long-term ethnography, it focuses primarily on dyadic, hierarchical exchanges between clients and service providers to the exclusion of the many other forms of language produced within institutional settings that are relevant sites of identity construction and ideological

reproduction. It is my hope that this work contributes to an expansion of the scope of this literature.

Description of Sample

Demographic Characteristics of Interviewees

A central goal of my research was to capture the perspectives of a broad range of HIV-positive individuals who differ from each other with regard to the demographic variables of gender, race/ethnicity and sexual orientation. To that end, my sample of interviewees is comprised of a significant proportion of women, people of color, specifically Latinos and African-Americans, and heterosexuals, in addition to gay men.

I should make clear at the outset that I make no claims that this sample of interviewees is statistically “representative” of either the wider population of HIV positive individuals in the U.S., or clients of GMHC. The small size of the sample precludes such generalizations, as does the fact that I made no effort to randomize the sample, or to compare HIVers’ language use with the speech data of any “control” group of individuals.

With regard to gender, my overall sample of 34 interviewees, including both GMHC clients and clients of others ASOs, is composed of 21 men (62%) and 13 women (38%). Of these individuals, 17 are white (50%) and 17 are non-white (50%); of the 17 non-whites in the sample, 10 (59%) are African-American, while 7 (41%) are Latino/a.

In terms of interviewees' sexual orientation, heterosexuals (17 or 50%) and gays/bisexuals (17 or 50%) are equally represented. Among the 17 gay/bisexual interviewees, 13 (77%) identify as gay, while 4 (23 %) identify as bisexual. It is important to note that none of those interviewees who identify as gay are women, although two women do identify as bisexual.

With respect to the variable of age the sample is less diverse. The 34 interviewees ranged in age from 29 to 55 years old. The mean age of the sample is 42.69, while the modal age is 46. The overall demographic composition of the sample is presented in Table 1 below.

Table 1. Demographic Composition of Sample of Interviewees

N = 34

	Gay/Bisexual Men	Heterosexual Men	Bisexual Women	Heterosexual Women
White	10	0	0	7
African-American	3	4	2	1
Latino/a	2	2	0	3

Limitations of Sample

Since a discussion of probable sources of bias in this sample of interviewees is included in Chapter 5 where I critically assess HIVers' narratives of self-transformation, here I will only briefly outline the major issues that will be elaborated upon later.

First, this project's sample of HIV positive interviewees is fundamentally linked to the institutional context of AIDS service organizations. As a direct consequence of my recruiting strategy, all the individuals who comprise the sample of interviewees are affiliated with and active participants in at least one AIDS-related service organization, the large majority as clients of GMHC. Indeed, many of these individuals were participating in activities at numerous such agencies at the time of their interviews, often in multiple capacities in addition to the role of "client" – for example, as "peer" counselors, hotline volunteers, or political advocates for people with HIV/AIDS. Because of their close ties to AIDS service organizations, sample members may represent HIVers who are more exposed to and influenced by the dominant discourse's construct of normative HIVer identity than other HIVers in New York City. In addition, since all of these individuals are active participants in on-site activities at GMHC or another city AIDS agency, they are necessarily physically able and tend overall to be in relatively stable health both physically and mentally. The sample does not include HIVers who are housebound or hospitalized due to illness; similarly, it includes only a very small number

of HIVers who appear, from my admittedly non-clinical perspective, to be in the midst of an acute mental health crisis.

Second, the sample of interviewees is self-selected, as individuals who saw my flyer at GMHC, or heard about my research through word-of-mouth, volunteered to participate in the study. Therefore, the sample may be skewed towards the inclusion of those HIVers who are coping with their HIV status in a particularly effective manner and are thus more inclined to talk about their feelings and experiences living with HIV to a researcher. It is also possible that such a self-selected sample is inherently biased towards individuals who share certain attitudinal or personality traits such as a particularly outgoing or loquacious nature.

For these reasons, I make no claim that the HIV positive individuals whose voices I have tried to capture in this study are necessarily “typical” of any wider group of HIVers. However, despite these limitations, this small and admittedly non-representative sample of HIVers is appropriate for the kind of qualitative, exploratory research engaged in here.

The Ethnographic Context of This Research: The “AIDS System” of Institutions and Gay Men’s Health Crisis (GMHC)

The “AIDS System of Institutions

According to Eric Rofes, the “AIDS System”, or “AIDS, Inc.”, is comprised of a variety of institutional forms, all of which are unified by their shared concern with some aspect of AIDS, either as a social phenomenon or a medical syndrome. This institutional system is comprised of “governmental AIDS bureaus, grassroots AIDS activist groups, publications targeting people with HIV/AIDS, medial professionals in hospitals and health clinics...AIDS groups, and self-help organizations of people with HIV/AIDS.” (Rofes, 1998: 270) The formation of a separate and autonomous system of institutions solely devoted to HIV/AIDS was an early and major accomplishment of AIDS activism in the 1980’s.

The roots of AIDS *service* organizations in particular, Rofes explains, are closely tied to the health and social service professions more generally. But “[d]uring the mid- and late 1980’s, AIDS work was removed from its original position embedded in the gay health field, as it began to produce its own freestanding system.” (Rofes, 1998: 230)

As Nancy Stoller (1998) notes, processes of increasing “professionalization” and “bureaucratization” have characterized the history of many ASOs, as they have grown from small, *ad hoc* volunteer-based movements to large, centrally located and

hierarchically organized institutions run by paid staff members, many of whom are professionals in the fields of social work, substance abuse counseling or mental health counseling.

Gay Men's Health Crisis (GMHC)

Gay Men's Health Crisis. First. Last. Always. The first response to the epidemic, started in 1981 – even before AIDS had its name. Today, we're still the first place people turn to. The last word in services for men, women and children affected by HIV in New York City, and in prevention and advocacy nationwide. We're always there when people need us. And, because AIDS is not over, we always will be.”¹

GMHC was founded in 1982 by the novelist, playwright and AIDS activist Larry Kramer who gathered together a group of his friends and associates – the “six gay white men”, according to the story I heard frequently when I was a regular participant in the daily life of the agency – to discuss the new “gay plague” that had yet to be identified².

Since its inception, GMHC has adhered to a three-pronged mission which correlates with a tripartite organizational structure oriented around HIV Prevention, which the agency still limits to gay men, HIV Treatment Education and the provision of Direct Services to HIV positive clients. This tripartite orientation is reflected in the agency's official mission statement which is quoted below:

“Gay Men's Health Crisis is a not-for-profit volunteer-supported and community-based organization committed to national leadership in the fight against AIDS. Our Mission is to reduce the spread of HIV disease, help people with HIV maintain and improve their health and independence, and keep the prevention, treatment and cure of HIV an urgent national and local priority. In fulfilling this

¹ Quoted from GMHC AIDS Hotline flyer. 1999, GMHC.

² This information is from “A Pocket History of AIDS and Gay Men's Health Crisis”, by Jacqueline L. Goldenberg and Daniel Wolfe. 1997. Gay Men's Health Crisis, Inc.

Mission we will remain true to our heritage by fighting homophobia and affirming the individual dignity of all gay men and lesbians.”³

One current organizational feature of GMHC that is particularly relevant to the present analysis, as I will address later in this work, is what I have termed an “identity-based” service structure according to which the agency has adopted a seemingly infinite particularization of services based on discrete social identities. For example, in 1996 GMHC established its Women and Family Services division which exists as a quasi-autonomous organization within GMHC with its own client intake procedure, its own floor in GMHC’s main building, and its own programs, such as Women in Action, a bundle of programs for HIV positive women who are former substance users and Child Life, for HIV positive parents and their children. Stoller’s description of this approach to social services as instantiated at the large ASO San Francisco AIDS Foundation is an equally apt characterization of GMHC; she says, “The programmatic expression of multiculturalism is seen...in the titles of the client service department’s programs: Gay/Bisexual Men of All Colors, Bilingual/Multicultural Services, Women and Children’s Services.” (Stoller, 1998: 41) From my experience at GMHC, I believe that this “balkanization based on identity”, to quote the words of a young GMHC staff member in the Public Policy department whom I came to know through my involvement with NYCAN, can function to factionalize clients, setting them apart from each other so that they do not interact and may even feel in competition with each other for increasingly scarce agency resources. Moreover, it is predicated on an essentialist,

³ Quoted from “Mission Statement of Gay Men’s Health Crisis, Inc”. As approved by the Board of

totalizing conception of identity, assuming that all women, or former drug users, say, necessarily share the same issues, issues that do not overlap with the issues of gay men, for example.

Having grown from a small grassroots, volunteer-run agency (albeit one formed by members of the gay cultural elite) to a major player in field of AIDS services, GMHC has become the largest ASO in New York City and, as the agency claims on much of its self-produced literature, the nation. These historical changes have been accompanied by a steady increase in the agency's size and budget. For example, in late 1996, shortly before I began this research, the agency moved to a new multi-story building in a prime, and expensive, downtown Manhattan location. As of April 1, 1999, the agency was serving a total of 5,993 HIV positive clients⁴. Reflecting Stoller's (1998) analysis of diachronic processes common to ASOs nationwide, GMHC has undergone processes of growing "professionalization" and "bureaucratization"; in fact, several respondents referred to the agency as a "bureaucracy" in their interviews.

Concomitant with its growth, GMHC has become part of the "AIDS establishment" – a transition that has not always been smooth; growth has produced bigger stakes, such as the agency's annual budget which hovers around 22 million dollars⁵, so that risks are necessarily harder to accept. However, the charge that GMHC's affiliation lies with the

Directors, 5/22/1995.

⁴ From *GMHC Volunteer: The Newsletter for Volunteers and Supporters of Gay Men's Health Crisis*, Spring 1999: 11.

⁵ *Ibid.*

mainstream is not new. In fact this debate flared early on in GMHC's history, leading to the angry departure of Larry Kramer in 1987 and Kramer's subsequent formation of ACT-UP. (Crimp and Rolston, 1990: 27) This friction represents a historical divide between AIDS activism and AIDS services, between those who want to challenge the system from "outside" and those who feel change can best be effected from "inside.

At the same time, the agency has experienced multiple shifts in its larger institutional context and its relations with other AIDS service organizations; after being the first and only agency of its kind when it was founded, the agency now faces increasing competition for government grants from a multitude of ASOs and community-based organizations (CBOs) in New York City. In 1999, as I was conducting the interviews for this project, GMHC was facing new problems of the "post-protease" era, particularly swift declines in public and private revenue which necessitated multiple rounds of cutbacks, layoffs, service limitations and ultimately, an agency-wide restructuring.

With the waning of AIDS activism in U.S. and the mainstream media's the limited interest in AIDS occupied by the ever-worsening ravages of "global AIDS" and the legal travails surrounding the production of generic antiretroviral drugs by foreign countries, the primary tension within the "AIDS system" now lies between "mega-ASOs" (Rofes, 1998) such as GMHC and smaller, more narrowly-focused CBOs.

In addition, GMHC has witnessed changes in its client body that parallel changes in the epidemiology of AIDS in the U.S. during the past two decades. Specifically, an increasing diversification of the “hardest-hit” communities has led to a gradual but marked increase in the number of heterosexuals, especially women, and people of color among the organization’s client base.

Chapter 3. The Dominant Discourse's Construction of HIVer Identity

Introduction

The goal of the three chapters that follow is an intertextual analysis of two forms of discourse of HIV/AIDS, comparing what I have termed the “dominant discourse” of AIDS which is produced in various institutional locations including AIDS service organizations (ASOs), local and national public health departments and mainstream media outlets, with the discourse of HIV positive ASO clients themselves, gleaned from the context of research interviews.

To provide a foundation for this intertextual analysis, the present chapter first lays out my theorization of the “dominant discourse” of AIDS. This is followed by a description of the fundamental tenets of the dominant discourse’s normative conceptualization of HIVer identity. It is my claim that dominant AIDS discourse constructs, and encourages HIVers to conform to, a model of the “good” or “proper” person with HIV/AIDS. This model establishes behavioral, affective and attitudinal standards which individual HIVers understand themselves in relation to and discursively position themselves against. In this manner, the dominant discourse legislates particular forms of subjectivity – including particular orientations towards one’s own HIV status and particular ways of being,

thinking, feeling and acting as a “person with HIV/AIDS” – as normative, or “preferred” for HIVers.

My conceptualization of the dominant discourse, as presented in this chapter, is based upon an analysis of printed, publicly-available textual data derived from a number of sources, including magazines and newsletters written for a primarily HIV positive readership, and a variety of agency-produced, and especially GMHC-produced, texts such as informational pamphlets about HIV/AIDS and its treatment, flyers advertising various GMHC services, and GMHC volunteer training materials. In addition, my understanding of ASO discourse in particular is informed by my personal recollections and fieldnotes from the participant-observation and volunteer work I conducted at GMHC in 1997 through 1999, as well as tape-recorded interviews with a small number of GMHC staff members and unrecorded, informal interviews with staff members of several other AIDS-related service organizations, including a needle-exchange site, in New York City.

This discussion of the dominant discourse is relevant to the central concern of this paper, namely, HIVers’ narratives of self-transformation, since these narratives are constructed in reference to, and thus fundamentally depend upon, the dominant discourse’s model of HIVer identity. Indeed, as I will demonstrate in Chapter 4, in articulating narratives of self-transformation, HIV positive individuals strive to portray themselves as embodying normative ideals. Interviewees’ narratives of self-transformation emerge from and are

shaped by the ideology of the dominant discourse, which is itself informed by a broader American ethos, even as they index and reproduce it; thus, they are simultaneously products of this ideology and agents of its reproduction. These narratives are specifically intertextual inasmuch as they index, or refer to, the collection of texts that constitutes the dominant discourse by either articulating characteristic themes of this discourse or by replicating, in part or in whole, stereotyped phrases associated with it. Interviewees' language use indexes not any particular text or texts but the dominant discourse as a whole, which, as I will argue, is comprised of an array of textual forms produced in multiple locations within the AIDS system of institutions.

The “Dominant Discourse of AIDS”

The “dominant discourse” of AIDS, as I conceptualize it, consists of a variety of discursive and interactional forms that are produced within multiple institutional locations both within and outside of the “AIDS system”. Considered, for heuristic purposes, as an abstract whole, this collection of texts functions to construct official knowledge of HIV/AIDS – either in a general sense or in relation to a specific and delimited aspect of the epidemic, as is the case, for example, with the “dominant discourse of HIV testing” in the U.S. which is constructed and propounded by the medical and public health establishments, as well as most AIDS service organizations, in this country.

My understanding of the “dominant discourse” of AIDS is deeply indebted to Eric Rofes’ probative critique of gay male community and AIDS organizations in his 1998 book *Dry Bones Breathe: Gay Men Creating Post-AIDS Identities and Cultures*. From him I borrow the term “AIDS system” (1998: 269) which he uses synonymously with the term “AIDS, Inc.” to refer the institutional arena that is comprised of “governmental AIDS bureaus, grassroots AIDS activist groups, publications targeting people with HIV/AIDS, medical professionals in hospitals and clinics, fund-raisers for AIDS groups, and self-help organizations of people with HIV/AIDS” (Rofes, 1998: 270); these are the institutions that produce the “dominant discourse” of AIDS. While Rofes does not develop a notion of a “dominant discourse” of AIDS *per se*, my understanding of this

discursive arena has been significantly influenced by his exegesis of the multiple institutional components of the “AIDS system”, its historical evolution and the recent crisis of legitimacy it has faced, particularly within certain segments of the gay male communities in “epicenter” cities”.

At this juncture, it may be helpful to clarify the two distinct senses in which I deploy the concept of “discourse” throughout this work. The first, a more literal sense, is roughly equivalent to “language” or “text”, and denotes both written and oral language use, as well as the form and content of language. For instance, as employed in the construction “the discourse of GMHC clients”, “discourse” encompasses multiple aspects of these individuals’ speech production – ranging broadly from its structural forms, to its referential content, to its indexical relations, its ideological components and its interactional functions. The second sense in which I use the concept of “discourse” derives from a loosely Foucauldian perspective, according to which “discourse” refers not to a discrete instance of speech, but rather to a ‘collection’ of texts that conveys and reproduces a particular ideological current. From this perspective, the “dominant discourse of AIDS” is an abstract entity that, in its entirety, exists only on a theoretical level; while specific texts, or collections of texts, that constitute the “dominant discourse of AIDS” are clearly identifiable, the “discourse” itself does not have a tangible, material existence. Moreover, this second sense of the term “discourse” accentuates the ideological aspect of language, the foundational, yet covert assumptions that

simultaneously undergird and emanate from the “discourse” itself, as well as the specific instances of language from which the larger discourse is comprised.

Note that two aspects of the “dominant discourse of AIDS” make a loosely Foucauldian conception of “discourse” a particularly apposite interpretive framework. First, is this discourse’s intimate connection to institutions of power within our society - influential institutions that have the power to shape individuals subjectivities, including their self-concepts, their interpretations of their own personal histories, as well as their behaviors and interactions with others. Second, is the formative role played by “experts”, individuals who command a specified arena of technical knowledge and language, in the formation of this “dominant AIDS discourse”.

The purpose of this discussion of dominant discourse is to lay out the central themes, assumptions and ideological framework of the dominant discourse so as to provide a basis for comparison with the narratives of self-transformation that are considered in the following chapter. The multiple points of thematic consonance between the dominant discourse and HIVers’ interview discourse substantiate my claim that the language use of HIVers indexes the official discourse of AIDS system institutions.

This, in turn, points to the substantial influence these institutions have on clients and HIVers in general. Institutions within the AIDS system, such as ASOs, produce multiple forms of discourse, ranging from spoken language, as occurs, for example, in face-to-face

interactions between clients and staff members and support group meetings, to the written texts that are my focus within this chapter, that is ideologically-laden and prescriptive. Clients “receive” this discourse either as interlocutors or listeners or as readers of written texts. Such discourse contains both explicit and covert messages regarding the “proper” or “best” way to be an HIV positive person. In its prescriptive mode, this discourse offers explicit behavioral recommendations, in the form of advice, tips or pointers, while more covertly, it conveys implicit assumptions about the ways in which HIVers should behave, think, feel, relate to others and so forth. In this manner, the dominant discourse constructs specific forms of subjectivity as normative, or “preferred”, for HIVers. The implicit and explicit messages contained in the texts of the dominant discourse fundamentally shape clients’ evolving self-conceptualizations, as well as their own discourse about HIV/AIDS. As the speech data from ASO clients’ interviews presented in Chapter 4 will demonstrate, clients frame their personal life stories in relation to the portrayals of “HIV identity” that are expressed in the dominant discourse.

My assertion that AIDS service organizations are not only aligned with dominant cultural ideology, but are also significant contributors to the “dominant discourse” of AIDS is supported by Rofes’ claims. According to his analysis, AIDS service organizations, and particularly “mega-ASOs” such as GMHC, are major producers and promulgators of hegemonic AIDS discourse. Most saliently, in his claim, they are the primary proponents of the outdated “crisis construct” of AIDS that no longer represents the majority of gay

men's experiences of the disease, whether they are HIV positive or negative. He further claims that this ideological stance is motivated by agencies' self-interest; he writes, "AIDS service groups, among the primary beneficiaries of panic and guilt-induced financial giving based on the crisis construct, [have] continued to find new ways to repackaging the epidemic-as-emergency and keep the dollars and volunteers flowing." (Rofes, 1996: 68-69).

This discourse can be characterized as "dominant" for two reasons. First, since it is produced and disseminated by institutional sites of power in society, the "official" imprimatur of the institution serves to legitimize the discourse's ideology as "fact", "knowledge" and "truth". Within the AIDS institutional arena, ideologies are often bureaucratized, that is, they are enacted in routinized procedures and documented in official texts by institutions including AIDS service organizations. As Mehan demonstrates in his analysis of the means by which the application of the label "learning disabled" is attached to individual children in the context of the school, such bureaucratic procedures, which are by their very nature routinized, inflexible, and resistant to creative interpretation, constitute and reproduce hegemonic ideologies in ways that are particularly resistant to change (Mehan, 1996:272). Processes of "entextualization" (c.f. Urban, 1996:21) by which these ideologies are encoded in written texts and official documents of the institution serve to codify and further concretize these ideologies as "real" or "natural". Secondly, as will be elaborated upon below, the

ideology conveyed in this discourse purports to universality; its partial and situated nature is concealed while alternative understandings are denied or renounced.

The language data which form the basis of my analysis in this chapter, and function as supplementary material in the following two chapters, derive from four distinct discursive arenas which I have identified as primary contributors to the “dominant discourse of HIV/AIDS”. These categories include “agency discourse” and “HIV discourse”, both of which are components of a broader “AIDS system discourse” (a concept which is elaborated upon below). Another discursive arena that is an especially fecund source of the foundational concepts, categories and ideologies that simultaneously define HIV and AIDS as social phenomena, and provide the terms through which HIV positive individuals define themselves and other HIVers, is that of medical literature and practice. Finally, I have relied to a limited extent on texts of the mainstream media where relevant to my interpretations. Although the mainstream media is distinct from these other discursive categories in that it does not emerge from institutions within or closely linked to the “AIDS system”, its inclusion is warranted for at least two reasons. First, throughout the 20-year history of the AIDS epidemic in the U.S., the mainstream media has most certainly played a significant role in the production of hegemonic images and interpretations of both HIV/AIDS and HIV positive individuals. Moreover, as will be demonstrated, there exist a number of fundamental ideological parallels between the discourse produced within the AIDS system and American popular discourse more generally – discourse that is, in large measure, shaped by the mainstream mass media.

The essential distinction between the “dominant AIDS discourse” and the “dominant AIDS system discourse”, as I define these concepts, is that the term “dominant AIDS discourse” is more inclusive, potentially encompassing a wide range of texts produced for a general readership in any number of institutional locations. In contrast, the term “dominant AIDS *system* discourse” specifically refers to texts produced by institutions within the “AIDS system” itself – institutions that are typically devoted to the issue of HIV/AIDS, including AIDS service organizations, and are largely geared towards serving the “AIDS community” (which includes individuals either “infected or affected by HIV/AIDS”, to use a common motto of AIDS agencies). Despite these differences in location of production and target audience, however, both the generalized “dominant AIDS discourse” and the more specific “dominant AIDS system discourse” tend in the main to share the same fundamental ideological tenets. For this reason, I have opted to use the more general designation “dominant AIDS discourse” throughout this work, except in those limited contexts in which the distinction is significant to my analysis.

Textual Varieties of “Dominant AIDS Discourse”

It is important to emphasize that, as mentioned above, the textual forms⁶ that constitute each of these discursive arenas are multiple, spanning a broad range of modes, genres, “speech events” and contexts of production and reception. However, for practical purposes, I have limited my analysis of dominant AIDS discourse to a consideration of readily-accessible printed texts, including magazines, advertisements on buses and subway terminals, and informational newsletters and flyers⁷.

Within the designation of “dominant AIDS system discourse”, I have identified a further distinction between “agency discourse” and “HIVer discourse”. These two discursive

⁶ For the purposes at hand, I do not adhere to a strict distinction between “discourse” and “text” in which, for example, “discourse” refers to spoken language viewed from the perspective of its interactional and cultural context, while “text” references the decontextualized “text-artifact” (Silverstein and Urban, 1996: 4) that results from some recording or encoding process that transforms the discourse into a material object. Instead, I use the terms “text” and “discourse” – the latter term is understood in its more literal and less explicitly ideological sense – in a roughly equivalent manner, to encompass a broad variety of linguistic modes, genres, and so forth.

⁷ As a caveat, I should point out that the “dominant discourse of AIDS” includes a multiplicity of texts and textual formats that I have not relied upon for the present analysis. Most prominently, since my focus with regard to the “dominant discourse” data is limited to written texts, I have not relied upon textual formats such as: television (including feature productions, commercial advertisements, public-service advertisements and community-produced cable TV shows); film; video (from instructional and motivational videos produced by service agencies to corporate-produced “social marketing” videos designed to change health-related behaviors – both of which are often screened for clients of social service organizations); or internet-based materials. This focus is not motivated by theoretical concerns, but by practical and personal, perhaps idiosyncratic, reasons – ranging from the ease of access and handling of printed data to my personal preference for the tactile experience of the printed page.

In addition, due to the strict rules of confidentiality within the AIDS institutional arena, I was unable to include tape-recorded data from socially-occurring verbal interactions among clients, staff and volunteers at GMHC, my primary research site. While I was granted access to weekly Parenting Group meetings at GMHC with the consent of the two “peer” co-facilitators and the regular group members, the content of this language data proved to be too far afield from my central concerns to be included in this paper.

categories are distinguished by a variety of characteristics, the two most salient being the institutional location of their production, and their intended audience or readership (i.e., agency clients versus HIVers in general and other interested parties). In addition, these textual categories typically vary according to their sources and amount of funding, factors which are influenced by their institutional locus of production, and which in turn influence the texts' production values, frequency of distribution and level of editorial control.

Since my analysis relies most heavily on "agency discourse" and "HIVer discourse", as befits my topical focus on the influence of AIDS institutions on HIVers' identity constructions, I will concentrate my description on these two categories of dominant AIDS discourse.

Agency Discourse

As instantiations of “agency discourse”, I have relied primarily upon written texts produced by GMHC and distributed either by mail to agency clients and volunteers, or on-site at the agency’s Manhattan headquarters. However, it is important to emphasize that GMHC produces ideological discourse through all levels of its work, from education – which encompasses both HIV prevention and treatment education for HIV positive clients – to clients services – such as “intensive case management”, the Buddy Program and free legal assistance – to advocacy – in which capacity the agency produces press releases and position statements and conducts lobbying visits with clients and volunteers to local legislators. Thus, the AIDS discourse produced by GMHC is multi-focal and intertextual; it concerns a range of topical foci, including safer sexual practices, dealing with health insurance companies and national immigration policy, and is promulgated through a range of textual formats, both spoken – such as public lectures and volunteer trainings – and written – such as the educational newsletters and leaflets the agency produces either for its direct constituency or the general public. All of this discourse is ideological inasmuch as it functions to ratify a normative vision of living well with HIV; just as educational and advocacy texts frame particular issues as relevant to people with HIV/AIDS, communicating to clients the issues they should be concerned with, so too do direct services aim to shape clients behavior in the direction of normative standards of “healthful” behavior.

HIVer Discourse

“HIVer discourse” consists of texts (I have relied mostly on periodicals in this paper) produced primarily for an audience of HIV-positive individuals; such texts may or may not be produced by HIVers themselves, or affiliated with an AIDS-related organization or foundation. However, I have distinguished publications such as treatment newsletters produced under auspices of ASOs – including GMHC’s own *Treatment News* – from bonafide “agency discourse” if the content of such newsletters does not concern the agency itself, and its production is at least semi-autonomous. Furthermore, “HIVer discourse” may be produced and funded by either non-profit or for-profit outfits. For example, two of the most widely read national magazines catering to an HIV positive readership, *POZ* and *A&U*, which I rely upon heavily for my examples of “dominant discourse” data, are for-profit ventures, while treatment newsletters are generally not-for-profit.

Included in the category of “HIVer discourse” are a variety of textual styles and formats, from glossy monthlies such as *POZ* and *A&U* that are financed primarily through pharmaceutical company advertisements, to treatment newsletters which typically have tighter budgets, smaller circulations with less frequent and sometimes irregular production of issues, and “do-it-yourself” production values. These financial constraints affect multiple aspects of the texts, including their physical appearance and the means by

which they are produced; typically these informal newsletters are usually ad-free and reliant on volunteer staff and writers.

Medical Discourse and Practice

Since a full-fledged consideration of medical discourse on HIV and AIDS is beyond the scope of the present project, I have intentionally backgrounded this aspect of my analysis. While I do make frequent reference to biomedical constructs in my interpretations of HIVers' identity constructions – they can hardly be avoided – I have made very limited use of primary texts representative of this discursive arena, such as articles from medical journals, as sources of textual data. Instead, I have elected to concentrate my attention on the ways in which biomedical conceptions of HIV and AIDS are interpreted and presented to HIVers by agents of the “AIDS system” through the various texts that comprise “HIVer discourse” and “agency discourse”.

Another motivation for de-emphasizing a direct analysis of the biomedical discourse on AIDS is the fact that this subject has been expertly treated by many other researchers and writers, including anthropologists, several of whom have provided cogent analyses of the dominant metaphors and inherent ideological frameworks encoded in biomedical discourse on HIV/AIDS (c.f. Kruger, 1996; Martin, 1994; Patton, 1990; and Waldby, 1996).

Mainstream Media

With regard to mainstream media texts, I have relied on well-known magazines and newspapers with mass national or regional distributions, such as *The New York Times*, the *New Yorker* and *Time Out New York* (a weekly events magazine that is widely read and available at most newsstands in New York City).

Themes of Transformation within the Dominant Discourse of AIDS

Central to the dominant discourse's ideology is a valorization of self-transformation.

Moreover, this discourse also supports the notion that an HIV diagnosis can function as a catalyst for such change. For example, a GMHC flyer geared towards African-American men entitled "Brothers Got To Work It Out!" notes that "Finding out that you have HIV can be an important step toward taking care of your health and planning for the future."

Similarly, the publisher of *POZ* magazine, a glossy monthly devoted to HIV/AIDS issues for those living with the virus, writes:

"My focus every day is to feel good and normal with this disease, to know that I have a future ahead of me, that survival is possible. I work hard at it...living to the fullest, moving from shame about getting HIV to pride at how I'm living with it..." (Brad Peebles' Publisher's Letter in *POZ*, July/August, 2003: 4)

He extends his evaluation to the readers of *POZ*, noting that "all of us...are busy trying to live a happy, healthy, well-adjusted life with this virus." Several key themes of the dominant conceptualization of self-transformation are illustrated in this statement. First, self-transformation consists of changes on both the behavioral and psychological levels towards an all-encompassing norm of "health"; in addition to being physically "*healthy*", HIVers should strive to be "*happy*" and "*well-adjusted*". Moreover, this transformation requires concerted effort; it is, quite literally, self-work, as evidenced in Peebles' use of words and phrases such as "*busy*", "*every day*" and "*I work hard at it*".

The idea that beneficial and socially desirable changes in the self can be effected through “work” is even reflected in the titles and brief descriptions of GMHC support groups provided through the agency’s Women and Family Services division. According to a monthly flyer posted at the agency and distributed to clients and volunteers, groups with names such as “Healing & Recovery”, “Self-Esteem” and “Promising Miracles” are available to clients who are “*working* on substance use issues” or “*working* through traumatic events/experiences” and “*need support*”, “*need help*”. Since such self-work is difficult, it is the agency’s job to provide HIVers with the various kinds of help that they need, whether it is in the form of emotional support, as in the case of “women and men living with HIV/AIDS who need help sharing their secrets”, or in the more practical realm of “information, testing and referrals”.

The fact that this theme of self-transformation subsequent to HIV diagnosis is evidenced in both “HIV literature”, as represented by *POZ* magazine, and GMHC-produced texts supports my assertion that these two textual categories are parts of a larger discursive arena characterized by a shared ideology.

Indeed, the assumptions about the nature of identity that underlie both the dominant AIDS discourse and HIVers’ narratives of self-transformation – namely, that individual identity is mutable, subject to change through the application of conscious effort, and that identity is an achievement, something that one must strive to attain – are widely held beyond the arena of AIDS discourse. They are fundamental to the modern American

ethos, as is the very notion of self-transformation itself. The theme of self-reinvention – instantiated in the cover of a recent issue of *Time Out*, the popular New York City events weekly which proclaims, “Re-Invent Yourself!” – is commonly expressed in mainstream texts of in American popular culture. This secular faith in the value of “self-work” is a particularly American brand of faith. Ultimately, it represents a faith in the power of individual will – a belief that attempts by individuals to alter both the circumstances of their lived reality and their personas are worthy, and a faith that such efforts will be rewarded.

This notion of self-reinvention is no doubt rooted in the American belief in class mobility that is represented in the Horatio Alger myth. Both ideologies rest upon a fantasy of limitless possibility and share a resolute faith in self-reliance – an individual can become anything he wants given the requisite determination and effort. In the ideology of self-reinvention, the belief in socioeconomic mobility of the Horatio Alger myth is extended to multiple facets of personal identity, from an individual’s external appearance to his or her relationships, psyche and spiritual awareness. An abundance of examples from American popular culture attest to a burgeoning popular interest in self-re-invention – from the ever-rising popularity of cosmetic surgery and dentistry, to the booming demand for psychotropic, mood-altering medications and “lifestyle-enhancement” drugs such as Viagra, to the surfeit of self-help books that populate the best-seller lists, focusing on topics such as finding a mate, relationship improvement, wealth-accumulation and spiritual growth. As these examples suggest, self-reinvention is inseparable from our

capitalist, consumer-driven economy; re-fashioning one's identity usually involves, and is frequently synonymous with, the purchase of material good and services.

The “Stages of Change” Model: A Case Study from GMHC Training

A more extended example of the dominant discourse’s explicit advocacy of individual change is provided by the “stages of change” model. While this model originated within the discipline of psychology, not within the AIDS service system, it has gained wide currency within the social services arena generally, and within AIDS services, more specifically.

My own initial exposure to this model was within context of AIDS services – specifically, at two GMHC events, both of which had an explicitly educative/didactic function. The first occasion was in 1997, during the course of my intensive training to become a volunteer for GMHC’s “Buddy Program”⁸. The second time was in 1999 at a similar event, GMHC’s annual “Buddy Program Training Retreat” which is designed to provide volunteers working as Buddies with an update on medical, social and other developments within the field of HIV/AIDS; on this occasion, the model was presented in a workshop on the topic of working with clients with drug abuse issues.

As presented in the context of this workshop, the “stages of change” model provides a template for understanding the common process underlying individuals’ attempts to

⁸ GMHC’s “Buddy Program” has long been one of the agency’s flagship services. In this program, an individual volunteer is matched with a client and serves that client’s needs on a one-on-one basis by engaging in activities such as visiting house-bound or hospitalized clients for emotional support, helping clients with routine household chores, or accompanying them on doctor’s visits and other outings. GMHC requires prospective “buddies” to undergo additional training beyond the standard training which is required of all agency volunteers.

change “problem” behaviors, including smoking, overeating and drug use. Particular attention in this workshop was given to the nexus of “compulsive behaviors and depression”⁹.

According to this model, individual behavioral change is represented as a progression of stages arranged in a circular formation. Movement towards the attainment of one’s goal is plotted on a clockwise trajectory through the five discrete stages that comprise the full cycle of change. The cycle begins with “pre-contemplation” in which “the client is not considering a behavior change” and a buddy’s goal should be “to get the client to start considering the costs and benefits of his/her behavior(s)” ; proceeds through the stages of “contemplation”, “planning and preparation” and “action”; and ends with the “maintenance” phase in which “changing continues and becomes normalized” and a buddy’s goal should now be to “offer the client continued support, especially in looking at triggers that might provoke relapse and thinking about how to avoid them, or replace them with other elements.”

The model’s circularity is meant to emphasize the recursive nature of self-change, in keeping with the medical model of addiction as an inherently chronic, relapsing disease. Thus, the model accommodates repeated iterations or cycles, as an individual can go through the process of change an infinite number of times, whether for the same problem

⁹ My discussion in this section, as well as the quotations, are from an unattributed hand-out entitled “The Stages of Changing Behavior” given to participants in the workshop “Sex, Drugs and the Blues” at GMHC’s Buddy Program Training Retreat on Saturday, February 6, 1999 by the group’s facilitator, Julia Ritchie, CSW.

behavior or for multiple behaviors. Also, movement within the circle of change can occur in both directions; as an alternative to the desired clockwise progression from the “contemplation” of a change through its “maintenance”, an individual may “relapse” by regressing backwards from any stage beyond “pre-contemplation”. Similarly, change may begin or end at multiple points within the cycle; for example, an individual who has relapsed may initiate a second attempt at change without falling all the way back to “pre-contemplation”.

Despite its circularity, the stages of change model is essentially teleological inasmuch as change is conceived of as goal-driven progression of stages. While the model accommodates some flexibility in terms of the directionality of change, the two directions of potential change are not equivalent in social value. As presented in the context of GMHC, the desired endpoint of clients’ behavior change is quite clear; it is the acquisition of normatively preferred behaviors and the relinquishment of dispreferred behaviors.

Finally, it should be noted that this model is all-encompassing; any and all behaviors an individual may be engaged in can be subsumed within one of its categories. If an individual does not wish to change a behavior normatively regarded as “unhealthy” or “destructive”, such as smoking or drug use, then that person can be considered, from the perspective of the model, to be in the “pre-contemplation” phase. Analogously, if an individual is engaged in a behavior that dominant social mores deem “acceptable” or

“appropriate”, then one may be considered to be in the “maintenance” phase. This point is significant since it accords with Whisman’s description of dominant identity accounts as those that have the capacity to “assimilate alternatives”, describing a wide range of experience in their universalizing vision (Whisman, 1996: 102).

This discussion of the stages of change model highlights one of many means by which ASOs such as GMHC advocate individual behavioral change as essential to clients’ wellbeing. The use of the model in agency trainings functions to focus volunteers’ attention on the need for clients to rectify or abandon “unhealthy” behaviors which are assumed to be the primary source of any problems they might be experiencing. Moreover, in advocating this model, GMHC endorses and explicitly inculcates in its constituents – namely, clients, volunteers and staff members – the model’s implicit ideology – an ideology of individual change that also undergirds interviewees’ narratives of self-transformation.

Foremost among the ideological assumptions of the “stages of change” model is an exclusive focus on the self as the primary locus of change. The notion that individual behavioral change, particularly in the realm of health-related behaviors (i.e., the adoption of “healthy” behaviors and/or the renunciation of “unhealthy” behaviors), is a “good” thing is assumed *a priori*. Because the value and desirability of such change is taken to be self-evident, any problematizing of this point is moot. Instead, behavioral change is constructed as “personal growth” – a laudable goal that leads to greater self-fulfillment.

In this strictly individualist model of human behavior, “problems” are located within the individual’s psyche and his or her behavior. Correspondingly, behavioral change is understood to result from the intentional application of effort and will on the part of the individual. Since “contemplation” is a sufficient predicate for change, any consideration of social context is relevant only insofar as it intrudes on the individual’s personal journey. Thus, the model encourages clients to look inside themselves, and only inside themselves, for the source of and the solution to their “problems”; in so doing, it implicitly denies the reality of structural sources of problems clients may be experiencing such as drug addiction, homelessness, or poverty. By denying the structural causes of social problems, such an ideology obviates the need for structural solutions, thus functioning to support the status quo. In addition, it may serve to reinforce “blame the victim” tactics in which problems that are, at least in part, socially-derived are seen to result from inherent flaws or weaknesses within particular individuals or groups. Indeed, despite its circular overlay, the “stages of change” model’s fundamentally teleological nature lends itself to polarized value judgments linked to specific stages of change in which the initial, “pre-contemplation” stage is conceived of as “bad”, and the end-stage, or goal, is understood as “good”. This serves to shore up a pervasive slippage between conceptions of physical health and moral worth that obtains within the realm of AIDS discourse, whereby “good” or “bad” behaviors come to stand for “good” or “bad” people.

The Dominant Discourse's Model of Normative HIVer Identity

As noted earlier, a key component of the discourse produced by the various institutions within the “AIDS system” is the construction of a normative model of HIVer identity, or a model of the ‘proper’ person with HIV/AIDS. This model functions to define a socially ‘appropriate’ way of living with HIV or AIDS that encompasses multiple aspects of identity, including behaviors, attitudinal stances and orientations to one’s life and one’s future. The discourse that communicates this model can be overtly prescriptive in its behavioral and attitudinal prescriptions – as, for example, in the panoply of tips and pointers for HIV positive individuals that pervade agency-produced literature and print media about the disease geared toward an HIV positive audience – or it can be more covertly ideological – as is the case in much ostensibly objective reporting about AIDS issues.

Crucial to the construction of this model are processes of repetition and mutual reinforcement. The normative model of HIVer identity emerges through an accretion of multiple messages contained in multiple and diverse texts of the dominant discourse; these individual texts contribute to and reproduce the dominant ideology, even as they are themselves products of it. As this discursive model is internalized, it becomes at once a mental model, a model *of* external reality in HIVers’ minds, and a model *for* their own behavior as they attempt to shape their behavior in accordance with its norms.

This discursive construction is particularly robust within the discourse of service organizations which is hardly surprising in light of the fact that these agencies fulfill an essentially rehabilitative function. A central aim of the client services provided by organizations such as GMHC is to “stabilize” an individual who in some sort of distress, be it physical, emotional, financial, legal, or another form of distress. By helping them overcome their problems, the agency’s goal is to assist individuals in “functioning” better so that they may rejoin the community of “normals”.

For example, a GMHC pamphlet published by the agency’s Women and Family Services Department entitled “Harm Reduction for HIV Positive Women” explicitly encourages women who are using drugs to make changes in their life:

“The truth is, you don’t have to be an alcoholic or a drug addict to make changes, and while stopping drinking or drugging might be the best thing you could do for yourself and your family it is definitely not the only thing you can do to stay healthier and *keep your life together.*”¹⁰ (italics added)

As this example suggests, AIDS service organizations, like social and mental health services more generally, have the explicit goal of fostering individual change.

Another feature of this normative model is its totalizing quality. First, the dominant discourse fails to recognize differences among HIVers. Instead, the discourse, by its very nature, addresses HIVers as an undifferentiated totality; its messages are intended to be applicable and relevant to *all* HIVers. Further, the voice of the dominant discourse lacks

nuance, as it typically contains no reference, or even allusion, to any contingencies, limitations or exceptional circumstances in which its normative dictates might not be applicable. Thus, the standards of behavior and identity established in the dominant discourse's normative model acquire both a universality and a compulsory force.

The goal of crafting a stable self that is in complete adherence to the dominant discourse's normative model of HIVer identity is an ultimately futile effort since the behavioral standards that comprise this model are necessarily subject to both synchronic debate and diachronic change. As is typical of hegemonic ideology, the dominant behavioral standards that emerge from such ideology are sufficiently vague, contested or fluctuating as to evade precise rendering or perfect adherence. In fact, according to Whisman, this lack of fixity is a significant source of the power of dominant cultural narratives, for in their very flexibility lies their totalizing capacity. As she claims, with reference to the "dominant" accounts of sexual identity formation articulated by the majority of gay and lesbian interviewees in her study, "...the dominant account...assimilates alternatives; there is no experience it cannot be used to explain. That is...the point of its appeal." (Whisman, 1996: 102). Extending her line of reasoning, it can be claimed that a corollary effect of this universalizing tendency is the construction of ever-elusive ideals of personhood, standards of normative behavior and subjectivity that, by design, cannot be fully embodied. It is this quality that fuels the constant striving for self-fulfillment that is

¹⁰ Harm Reduction for HIV+ Women: Making Choices and Making Changes, GMHC.

both a feature of contemporary American society and an ideological underpinning of HIVers' narratives of self-transformation.

With regard to the specific components of the dominant discourse's normative model of HIVer identity, since a discussion of several themes of the model are included in Chapter 4, this chapter's discussion will be limited to one predominant feature of this model – namely, the construction of being on combination therapy for HIV as normative for all HIVers.

HAART as Normative

Taking HAART¹¹ – that is, being “on meds”, to quote the common parlance – is a central component of the hegemonic model of “proper” HIVer identity. Not only is this behavior constructed by the dominant discourse as normative and expected for all HIVers, its dominance and its value has largely gone unquestioned in any serious, system-wide manner. Thus, HAART is presented by the dominant discourse as an utterly essential component of treatment without which continued “health” is not possible. This equation of “health”, and indeed life itself, with the ingestion of antiviral medications, in effect, constructs HAART as mandatory for all HIVers, regardless of their health status in general.¹²

¹¹ The acronym “HAART”, which stands for “highly active antiretroviral therapy”, is currently the standard biomedical designation for most combination anti-HIV drug therapy. The acronym was coined in 1996 after the advent of protease inhibitors and the resulting emergence of triple combination drug therapy as the standard of care for the treatment of HIVers who meet benchmark criteria based upon viral load and CD4 cell counts. Throughout this paper, I use “HAART” to denote *all* pharmaceutically-based antiviral combination regimens, regardless of the classes of antiviral medications that are used. While the term HAART was introduced into the medical register of HIV treatment to refer specifically to protease-based regimens, my own use of the term accords with a more generalized popular usage that appears to be gaining ground with the continued development of new classes of antiretroviral medications which have facilitated the use of non-protease-containing regimens.

¹² It is significant to note that the U.S.’s Federal HIV treatment recommendations, which indicate the specific CD4 and viral load levels at which the initiation of HAART is advocated according to dominant medical opinion, have been adjusted several times in recent years. Each of these revisions has favored a more conservative use of the medications (i.e., advocating the initiation of HAART at ever later stages in the course of the disease) in response to both a gradual waning of the hype that immediately followed

the release of protease inhibitors in 1996 as well as a growing recognition of the drugs' toxicities and side effects.

Taking combination therapy is heavily naturalized within the dominant discourse which presumes that any and all HIVers either are on HAART or would be if they could; the only reasons for not being on HAART that are seriously addressed are specific physiologic or behavioral problems with the therapy such as viral resistance, intolerable toxicities or adherence problems. Ideologically, this social norm is rooted in a certain 'pharmacentricity' that is characteristic of Western medicine and contemporary American culture in general; it thus stands as another example of ideological concordance between the dominant discourse of AIDS and American popular discourse.

Even more significantly, this emphasis on drugs as representing both 'salvation' for individual HIVers, and as society's best hope for ending the AIDS crisis on a global scale, has also been an early and enduring tenet of AIDS activism, from its early incarnation in radical protest-oriented groups such as ACT-UP to more recent movements such as such as the "treatment activism" of ACT-UP spin-off Treatment Action Group (TAG) that is less radical and more 'insider'. This "pharmacentricity" is in keeping with the central goals and assumptions of early AIDS activism which are aptly represented by the old ACT-UP battle cry "drugs into bodies". (Crimp & Rolston, 1990: 37) Among the primary goals of ACT-UP in the 1980's and early 1990's was increased governmental funding for research and development into medical, and especially pharmaceutical, therapies for the newly-identified syndrome. Fueling these demands was a faith in science, and particularly Western allopathic medicine, a belief that therein could be found the ultimate 'solution' to the AIDS crisis.

Rofes understands this narrow faith in pharmaceuticals, a belief that drugs alone have caused all recent improvements in the longevity of HIV-infected individuals and that drugs alone represent our best or only hope for managing HIV and AIDS in the future – a notion he dubs the “cure construct” – to be the lynchpin of hegemonic “AIDS system” discourse. Rofes attributes this myopic focus on pharmaceuticals to multiple sources, including influence of “Big Pharma” – major pharmaceutical companies whose glossy ads for the latest formulations of antiretroviral drugs keep *POZ* flush and, at the time of my research in 1997 through 2000, plastered many of the subway terminals and bus shelters in my Brooklyn neighborhood of Fort Greene – a historically African-American neighborhood with a growing influx black gay male residents. (Rofes, 1998: 54-56) From his perspective, such a blinkered view is dangerous as it instills false hope while neglecting the significant epidemiological shifts, especially the decline in death rates due to AIDS, that preceded the introduction and widespread use of protease inhibitors and combination therapy. Moreover, he maintains that the dominant AIDS discourse’s limited focus on quick biomedical fixes to AIDS has negative ramifications for HIVers themselves. As he says:

“We do people with HIV a disservice when we insist that the epidemic will remain static until the miracle of medical research serves up a cure... Why aren’t we aiming to support a narrative that focuses on the diminution of AIDS’ impact in our individual and collective lives, a respite from the AIDS-as-crisis story, rather than clinging obsessively to a less realistic goal of total elimination?”(Rofes, 1998: 65).

This myopic focus on pharmaceuticals as presenting *the* solution to the AIDS crisis has also served to reinforce the truth value of Western medicine. While AIDS activism has historically challenged many *practices* of the U.S. public health bureaucracy such as the FDA process for the approval of new pharmaceuticals and the procedures by which clinical trials for experimental drugs are carried out, it has failed to present a concerted challenge to Western medicine's claim to the "truth" of AIDS. As a result, the tenets and ideology of Western medicine have powerfully shaped AIDS discourse well beyond the medical arena (as the example presented below of the current reification of the achievement of an "undetectable" viral load will demonstrate).

Data from my sample of interviewees supports the contention that this widespread embrace of pharmaceutical treatment has facilitated the creation of a new behavioral norm for HIVers, whereby taking HAART regimens has become expected, even mandated. First, worthy of mention is the fact that the majority of interviewees within my sample were on a HAART regimen when they participated in the study. Of the 34 interviewees 29, or 85 percent, were on some form of combination therapy at the time of their interviews; what is more, all but two of the five HIVers in the sample who were not on HAART had been on them before in the past.

More importantly, interviewees' discourse makes clear that HIVers themselves orient to HAART as the normative behavior, regardless of whether they themselves are on a drug regimen or not. In fact, this orientation is most pointed among those individuals who are

not on antiviral medication for whatever reason and who overwhelmingly interpret their situation as ‘deviant’.

For instance, Ken makes a special point of noting, in two distinct points in his interview, that he is usually on combination therapy, but is currently taking an eight-month “drug holiday” to mitigate the liver toxicity he experienced as a side effect of the medications.

He says,:

“This medicine has a lot of side effects, so much that I stopped taking it, and I’m starting up again in – after the biopsy I’m going to start because I want an eight-month holiday. I only took the medicines for three years and I’m – I’m resistant to two already, so this is just a temporary thing.”

In emphasizing the fact that being off antiretroviral medication is merely a “*temporary thing*”, an aberration from his customary behavior, Ken normalizes his apparent failure to comply with the standard which holds that all HIVers should be on HAART, presenting himself as typically – and ultimately – adherent to its dictates. Furthermore, his use of the phrase “holiday” – an abbreviated variation of the term “drug holiday” – to index the dominant medical discourse serves similar ends in two ways. As a discursive strategy, this bit of technical jargon simultaneously displays his familiarity with the medical register of pharmaceutical HIV treatment and frames his departure from the normative behavioral standard within the accepted terms of the medical paradigm. Since a “drug holiday” is considered, from the perspective of the dominant discourse, a bonafide reason for (temporarily) discontinuing HAART, Ken legitimizes his own behavior by framing it as an allowable deviation from the norm.

Similarly, in the following passage, Evette, who has never been on antivirals, but instead swears by a holistic herbal regimen of her own devising, jokes that she is on a permanent “medication holiday” of sorts.

Ev: Because, like, for instance, ever since I was diagnosed, I never took medication. I take my medication, I’m a medication holiday (LAUGHS). That’s how I take medication.

Ed: I never heard you say that before! (LAUGHS)

Evette’s joke reveals that she is quite aware of the fact that her avoidance of antiviral medication constitutes “deviant” behavior from the point of view of the dominant discourse. Her partner Edgar’s reaction to her tongue-in-cheek statement is particularly noteworthy, as it underscores the significance, in his mind, of what she has said, marking her joke as a good one – a clever re-framing of this token of the medical jargon of HIV treatment. Ironically however, by framing her conscious and deliberate flouting of this normative behavior in the concepts and terminology of the dominant medical discourse, she in effect reproduces the hegemonic construction of this behavior as normative.

One negative consequence of this discursive construction of HAART as normative for HIVers is the ease with which this norm can morph into a mandate. It can be interpreted by individual HIVers as a compulsory behavioral dictate, and according to several interviewees, many medical providers regard it as such, exerting heavy pressure on their patients to go on HAART despite their sometimes tremendous reluctance and fear. Indeed, testimony from interviewees suggests not only that many HIVers feel compelled

to start HAART by dint of social pressure from multiple sources, including their doctors, agency caseworkers, their families, or fellow HIVers, but also that women seem to be particularly vulnerable to this pressure. A significant number of interviewees, and virtually all of the women in my sample, say they have felt pressured by their doctors to go on HAART, or are treated badly by them if they resist.

In the following passage, Tina describes a situation that amounts to extortion; her (now former) doctor at one point adamantly refused to draw blood for T-cell count unless and until she went on HIV medication – despite the fact that CD4 counts are a routine form of regular medical monitoring recommended for all HIVers regardless of whether they are on anti-HIV medications or not.

“So my doctor wouldn’t give me – at one point she didn’t want to take my T-cells because she said, What am I going to take your T-cells? I don’t even want to see your T-cells. If you’re not going to take medicine, why should I run you these tests, you know? So, okay, I told her, Look, I’ll – I was very scared also of the medicine because I had an inflamed pancreas and I was afraid the medicine was going to make the pancreas worse. So I said to her I’m not going to – um, I’m not going to take it, so then I decided, okay, I’ll start with the AZT, so I took the AZT...”

Carla elaborates at great length on her intense fear of HAART throughout her interview. In the example below, she admits that she even has brand new prescriptions for antivirals sitting in her medicine cabinet at home that she has not yet been able to bring herself to swallow.

“...I have some HIV meds in my house, but they’re like inside a little cabinet in my bedroom ‘cause I look at that shit with fear and I’m afraid of them, and it’s, I know some of them can make, supposedly get you to the level of being undetectable, but then what happens after that, you know? You know, maybe you’re telling me that they’re undetectable but maybe the medications is just putting a mask on the virus. The virus is actually still there.”

Significantly, Carla only reveals that she has these medications at the end of her interview, after she has already been discussing her extreme ambivalence about HAART for approximately a half hour. Her reluctance to admit to how close she is to beginning HAART is most likely motivated by the fact that she interprets her acceptance of the prescriptions as a failure of will. She presents this less-than-complete acquiescence to her doctor’s demands as a moral capitulation, as though she has in a single moment of weakness betrayed the years she resisted intense pressure to go on the medication.

“Undetectable”

Reaching and maintaining an “undetectable”¹³ viral load has become the prime goal of the dominant approach to the pharmaceutical treatment of HIV. According to a special issue of *POZ* magazine entitled “Lab Work Made Easy”, “Everybody these days has their eyes on the prize: Being undetectable.” (*POZ*, Summer 2002: 15) As if to illustrate this fact, a recent issue of the magazine features an advertisement for Kaletra, a protease inhibitor manufactured by Abbott Laboratories, which depicts a beaming young man, chin upturned and eyes to the sky, his arms raised in a victory pose with the word “Yes!” in red letters positioned next to his radiant smile; emblazoned on his chest is the caption, “Still undetectable. The virus is under control. My HIV therapy is still working. And Kaletra is helping to make a difference.”

Interview data from HIVers illustrates the extent to which the pursuit of an undetectable viral load functions as the holy grail of HIV treatment for both medical professionals and HIVers alike. As Edgar puts it, “...I thank God for the combination therapy for me because my viral load, I mean, my viral load has been as high as fifty-thousand, you know, and today I thank God that it’s undetectable uh due to medications, they work for me.” As he elaborates, it becomes clear that he views his attainment of an undetectable viral load as an achievement which he was able to accomplish as a result of his perseverance and willingness to take a chance. He says,

“...you have to look within yourself and say, Well, this ain’t helping, this ain’t helping, so I need to take the chance of trying to find out what’s helping...or talk to some people that’s on the medication you doctor’d like to put you on, and you need to find out because if things are getting worse – I hate that word (LAUGHS) – if things are not getting so good, then you need to find out something that will work for yourself.”

The case of “undetectable” illustrates a common phenomenon within AIDS discourse – namely, the transmutation of medical classifications and diagnostic categories into “identity labels”. This phenomenon is itself part of a more general process by which concepts, principles and categories originating in discursive arena of biomedicine are metaphorically extended to other realms of experience. The “undetectable” designation is represented in both the dominant discourse and by HIVers themselves as a badge of pride because it is understood to constitute tangible, ‘scientific’ evidence of one’s “success” at HAART, and, by extension, one’s ability to “adhere” to a drug regimen. Thus, “undetectable” has become something more than a measure of viral load; it has come to represent an individual’s success as a person, even his or her moral worth. This discursive metamorphosis occurs via a series of metaphorical shifts. First, within the medical discourse of HAART, an “undetectable” viral load is held out as the preeminent measure of an individual’s treatment “success”; indeed, such a reading is the *de facto* goal of antiviral treatment – particularly for those HIVers who are asymptomatic when they initiate therapy.

¹³ Having an “undetectable” viral load means that the level of HIV in one’s bloodstream is too low to be

Further, this “brass ring” of antiviral treatment is commonly viewed – by both patients and providers – as a gold star awarded to “good patients” since, according to the current medical conceptualization of viral resistance, an “undetectable” viral load is widely understood to reflect, in part or in whole, a patient’s “compliance” with treatment, as represented by his or her “adherence” to the prescribed regimen. “Adherence”, in turn, has become a shorthand index for an individual’s “success” as a “patient”, serving as a marker for a patient’s level of responsibility as well as his or her ability and inclination to follow orders, both factors thought to impact an individual’s ability to “adhere”. Since a “good patient” is tantamount to a “good person” within the dominant medical paradigm, a discursive slippage from “good patient” to “good person” is common in the quotidian practice of medicine as it is in clients’ interview discourse.

Furthermore, as Rofes points out, one’s degree of “success” on HAART, and thus the categorization of “undetectable” as well, can become a vehicle for social fragmentation among HIVers. While Rofes restricts his analysis to communities of gay men in “epicenter cities”, I believe his conclusions are more widely applicable to HIVers in general. He quotes an HIV positive man who says this about HAART,

“ These treatments are simply creating a new way to divide people with HIV into ‘good people with HIV’ and ‘bad people with HIV’. I’m one of the baddies because I screwed up my regimen and killed my chances for participating in what many people are seeing as the cure.” (Rofes, 1998: 111)

Chapter 4. Clients' Narratives of Self-Transformation

Introduction

This chapter examines the phenomenon by which a significant number of study participants present their life stories, in their interview discourse, around the central theme of “self-transformation”. In these “narratives of self-transformation”, as I term them, HIV positive individuals who are clients are AIDS-related service organizations construct their HIV diagnosis as a catalyst for a major “life turnaround”, in the words of one GMHC client.

Upon diagnosis, HIVers are faced with a phenomenological dilemma, as they are confronted with the identity-altering knowledge of their HIV positive status which challenges them to re-work their understandings of themselves and their life stories, including both their pasts and their projected futures. This dilemma has two distinct facets – one biographical and one social. First, they need to make sense of their lives which now have (sometimes profoundly) different future prospects and anticipated life trajectories. They need to create a coherent personal narrative, or life story, in the face of what writers on AIDS have termed a “biographical disruption” (Adam and Sears, 1996) or a “crisis of meaning” (Schwartzberg, 1996). With regard to the social dilemma, they need to integrate the new knowledge of their HIV status into their existing self-concepts, to construct new identities as “people with HIV or AIDS”.

An added difficulty is the stigmatizing effect of HIV itself. An HIV positive serostatus is stigmatizing, in large measure, because of the disease's longstanding association with particular groups of people, most saliently homosexual and bisexual men and IV drug users – the so called “high-risk” groups, to use the rhetoric of the early public discourse on AIDS. This association was established in American popular discourse in the first years of the epidemic (Guarino, 1995) and it remains in place today. Although the harshly condemnatory tone of the 1980's rhetoric around risk groups has moderated, the basic notion of AIDS as a disease of societal “others” lingers. In fact, one could argue that, if anything, this association solidified in the past five to ten years, as AIDS has faded from the forefront of American consciousness and become more firmly entrenched, both epidemiologically and rhetorically, as a disease of local or global “underclass” populations, a plight of the inner-city and the Third World. Since HIV is generally perceived as less of a threat to the “general public” in the U.S. today than it was in the height of the “heterosexual AIDS” panic of the late 1980's and early 1990's, the identification in the popular imagination of AIDS with particular socially stigmatized groups of people is reinforced. While HIV has indeed spread beyond the original “risk groups”, the particular communities that have been hardest hit are disproportionately poor communities of color – communities whose members are “otherized” by virtue of their socioeconomic class, or racial/ethnic identities.

Framing one's life and identity according to a narrative of self-transformation is one means of managing this dilemma, providing a way of re-inventing oneself upon an HIV diagnosis. Interviews with study participants suggest that this is a common strategy used

by a variety of HIVers from different backgrounds, as will be explored in greater depth in this chapter. Indeed, it is one of the most prominent discursive features within the interview data.

Within narratives of self-transformation, interviewees' life stories are characterized by a major shift – a “before” and “after” HIV. HIV diagnosis is constructed as the pivot around which their life stories hinge, the initiating event that spurred them to create a new and better reality for themselves and made them the people they are today. Typically, this involves a process of re-interpretation in which an event that was initially experienced as traumatic and terrifying is, over time, endowed with a more salutary meaning. Thus, HIV diagnosis serves a dual function in these narratives; it is at once a narrative event within the overall plot structure of an individual's life story, the climactic event determining the rest of the story, as well as the basis for a changed identity, the individual's new HIV positive self.

In their interviews, clients use two distinct plot structures in narrativizing the separation from their old lives and selves propelled by their HIV diagnosis and the subsequent process of transformation they have undergone. The essential distinction between these two forms rests in the manner in which they experience the phenomenological dilemma attendant upon an HIV diagnosis. This dilemma may be presented as immediately following in the wake of one's first HIV positive test, or it may proceed from an individual's gradual recognition and acceptance of his or her diagnosis. Expressed

another way, narrators' testimony reveals that the disjuncture from their prior identities and life stories impelled by an HIV diagnosis can either be experienced shortly after an individual first learns of his/her HIV status, or it may be a delayed reaction, arriving months or years after an individual's official diagnosis, following a period of "denial", to quote a term consistently used by those interviewees who relate this type of experience. These alternate narrativizations provide the basis for my distinction between "standard" and "deferred" narratives of self-transformation, as will be explored in greater depth in this chapter.

An essential feature of these narratives of self-transformation, one that unifies all specific instantiations of this form, is the fact that they construct HIVers' identities in conformity with the dominant discourse's normative model of HIVer identity that is delineated in Chapter 3. Thus, these narratives are not value-neutral, but deeply ideological, serving to reproduce the dominant ideology and moral economy upon which this model is based. Moreover, for certain individuals, particularly, as will be shown, for those with histories of substance abuse, narratives of self-transformation present an HIVer with the opportunity to cast off a stigmatized identity and life history and to re-invent herself according to mainstream social values. In my analysis, I will present excerpts from clients' interviews in which they orient to this normative model, constructing self-presentations that are consonant with its fundamental ideological principles. This speech data constitutes further evidence of the model's existence and its relevance to HIVers' identity constructions through discourse.

In relating these narratives of self-transformation, interviewees are simultaneously displaying their transformed identities and constituting them, as each telling “construct[s] a fluid, evolving identity-in-the-making.” As Ochs and Capps make clear, “selves evolve in the time frame of a single telling as well as in the course of the many tellings that eventually compose a life.” (Ochs and Capps, 1996: 22 and 23)

The Dominant Identity Narrative: Standard Narratives of Self-Transformation

Patterns of Use of Narratives of Self-Transformation

A central claim of this work is that narratives of self-transformation represent a dominant mode of identity construction for HIV positive clients of AIDS service organizations (ASOs). I use the concept of “dominance” here in two distinct senses. First, I am referring to the simple prevalence of this discursive form in my sample of interviewees, all of whom are clients of at least one AIDS service organization and the majority of whom are clients of GMHC, the nation’s oldest and arguably largest centralized multi-service ASO¹⁴ As noted above, the use of narratives of self-transformation is one of the most salient features of interviewees’ language use. Supporting this claim is the fact the majority of interviewees in my sample articulate narratives of self-transformation; of my sample of 34 HIV positive interviewees, 21, or 62%, use either the “standard” or the “deferred” variety of this narrative form.

From a somewhat different perspective, narratives of self-transformation can be considered a dominant pattern within clients’ language use inasmuch as they reference and support dominant ideology, including both the “dominant discourse” of HIV/AIDS

¹⁴ See Chapter 2 for a discussion of AIDS service organizations in general, as well as a description of Gay Men’s Health Crisis (GMHC) in particular.

that is produced in large part by the AIDS institutional system, as well as elements of a broader American cultural ethos from which the dominant discourse of AIDS emerges. On the one hand, these narratives of self-transformation function to construct and present HIVers' own identities as exemplifying the hegemonic model of 'proper' HIVer identity that was the topic of the previous chapter. Moreover, in so doing, they simultaneously function to reproduce and perpetuate the dominant ideological framework that underlies this normative model of HIVer identity.

As a dominant feature of clients' language use in interviews, narratives of self-transformation are articulated by a diversity of HIVers, as measured by differences in gender, race/ethnicity, sexual orientation and socioeconomic class. The following table indicates the composition of the subgroup of interviewees who use narratives of self-transformation by gender, race/ethnicity and sexual orientation.

Table 1. Demographic Composition of Users of Narratives of Self-Transformation**N = 21**

	Gay/Bisexual Men	Heterosexual Men	Bisexual Women	Heterosexual Women
White	6	0	0	2
African-American	3	2	2	2
Latino/a	2	1	0	2

However, within this demographic diversity, some systematic patterns of use can be discerned. Narratives of self-transformation are used primarily by two groups of HIVers in my sample – namely, gay or bisexual men and former substance users¹⁵. These groups are fairly distinct, with a minimal degree of overlap; thus, their members differ from each other in systematic ways with respect to the variables of gender, race/ethnicity, sexual orientation and socioeconomic class¹⁶. To wit, the subgroup of gay or bisexual men who

¹⁵ I use the designation “former substance users” in this context to refer to those interviewees who by self-report, indicated that they had histories of significant use or dependence on drugs or alcohol and who, at the time of their interviews, labeled themselves as “abstinent” and/or “in recovery”.

¹⁶ My method for assessing interviewees’ socioeconomic class merits particular attention, as this variable is notoriously difficult to measure accurately and directly, as many researchers within linguistic anthropology and the social sciences more generally have noted (see, for example Milroy 1980:13-14). The unreliability of individuals’, and specifically Americans’, self-reports of class membership is just one example of the problems faced by researchers attempting to grapple with this issue. Since an in-depth consideration of the problematics surrounding both the construct of socioeconomic class as a discrete variable, as well as its

use narratives of self-transformation is comprised of more white men than either African-American or Latino men. Most of the gay/bisexual men of all races are from middle-class backgrounds and have professional work histories (although, in the majority of cases, these clients with professional work histories are no longer working, as they have received diagnoses of “full-blown” AIDS which qualifies them for public or private disability.) The former substance users, in contrast, are typically heterosexual men and women of color from the lower socioeconomic strata, whose interviews reveal a number of common experiences associated with poverty, from histories of long-term unemployment and/or dependence on public assistance, to episodes of homelessness, and current residence in “scatter-site” or “supportive” housing for people with AIDS paid for by the Division of AIDS Service (DAS) which is administered through New York City’s welfare department.

measurement, is beyond the scope of the present work, I will only briefly outline my strategy for addressing socioeconomic class in this research.

If socioeconomic class is difficult to measure in general, it is even more challenging in the context of HIV/AIDS which itself has a tendency to produce downward mobility, as individuals – especially those who have been HIV positive for ten or more years, as have the majority of gay white men in my sample – become too ill to work and are forced to support themselves on the fixed income provided by disability insurance. In light of these complicating factors, I chose to eschew quantification of this variable entirely. Instead, when socioeconomic class is relevant to a particular analysis, I have elected to use a more qualitative approach involving the exposition of multiple “proxy” variables that are closely linked to class within the social context of present-day urban U.S. These variables include: length and nature of employment history (prior to the onset of AIDS where applicable); educational level; pre-HIV reliance on public assistance; and a history of criminal activity and/or time spent in prison. Additionally, as the vast majority of sample members were receiving some forms of public or private medical insurance and/or disability income at the time of their interviews, I have also taken into consideration the specific kinds of benefits an interviewee was receiving. Since the kind of benefits and entitlements an HIV positive New Yorker receives is directly related to his or her income level and employment/earning history, these differences can also be suggestive of an individual’s socioeconomic class background. However, while all of these variables are class-linked, none of them, even in the aggregate, can be appropriately understood as direct or uncomplicated indices of membership in any given socioeconomic stratum. Moreover, in some interviews, I did not obtain reliable data for each of these variables. Therefore, I have again declined to quantify them, choosing instead to make note of these variables within the text where relevant to my analysis.

While the popularity of narratives of self-transformation among former substance users and gay or bisexual men is, to be sure, in large measure a reflection of both the composition of my sample as a whole, and more broadly, the epidemiology of HIV in New York City, there is a salient distinction between the sample as a whole and the subset of interviewees who use narratives of self-transformation. None of the five women (three of whom are white and two of whom are Latina) who were infected with HIV by their male, IV drug-using sexual partners uses a narrative of self-transformation, as will be explored further in Chapter 5.

With regard to drug and alcohol use, it is important to note that none of the interviewees who use narratives of self-transformation identify themselves as current users of drugs or alcohol; instead, all of the narrators with histories of drug or alcohol use indicate that they are “in recovery” and abstinent from their substance of choice at the time of their interviews. (In fact, only two interviewees in the entire sample admit to being active drug users and neither of them articulates a narrative of self-transformation.) In other words, within my sample, narratives of self-transformation are notably absent from the discourse of active drug users; this pattern of use is not unexpected given the theme of moral rehabilitation that lies at the heart of so many of these narratives, particularly among those interviewees who have histories of substance abuse; indeed for these individuals, their transformations hinge on their abstention from addictive substances.

Central Themes of Narratives of Self-Transformation

HIV as a Catalyst for Life Change

In the following passage, Arlene, a 46 year old mother and grandmother who had had been a homeless heroin and cocaine addict before testing positive, explains:

“It’s a shame to say, but if it wasn’t for HIV in my life, I don’t know where I might be in life. (LAUGHS) I don’t think I would be taking as, as great a care of myself as I am now, you know. It’s a shame it had to be such a tragic [thing] that causes you to care about yourself, but it was one disease that made me want to live instead of making me want to die, you know. Where before, when I didn’t have it, I didn’t care about anything, you know? But I care about living with this disease and trying to beat it, maybe it’s a challenge to my life, you know, and I think almost having it fifteen years I’m considered a long-time survivor, and I think that’s something to say.”

(Arlene, 46 year old bisexual African-American woman)

She sees living with HIV as a challenge, one that gives her life an overarching sense of purpose. While, as she describes it, she had no real goals before her diagnosis and “didn’t care about anything”, now just surviving and living well with the virus is experienced as an achievement, her success at which is a source of self-esteem. Indeed, as a woman who has lived with full-blown AIDS for thirteen years, she presents her classification as a “long-term survivor” as a badge of pride.

William, a 49 year old Latino musician, describes his own transformation in these words:

“My outlook on life has changed from being wild and destructive to becoming grateful, and fortunate that I’m still around, being content with, you know, myself that it has – it’s slowed me down a lot, whereas I think if it wasn’t for this, for the bad news I had received, I couldn’t have survived, you know. So this here has become a lesson to be taught. And this was a blessing...”

(William, 49 year old heterosexual Latino man)

In this passage William articulates some of the most central themes of Narratives of Self-Transformation. First, he constructs his HIV diagnosis as a catalyst for a total life change, one that encompasses both his concrete behaviors as well as his outlook on life. He credits his HIV status with his abandonment of his earlier “wild and destructive” lifestyle, his newfound appreciation for life and indeed, his very survival. Furthermore, he presents his narrative of self-transformation as a morality tale – “a lesson to be taught”, and the substance of this lesson is that his earlier life was irresponsible, and immoral – a theme which strongly echoes the dominant discourse of HIV Prevention in which “risky” behavior, such as knowingly engaging in unprotected sex, is frequently presented as immoral inasmuch as it constitutes a threat to oneself and others.

As Raul, a 55 year old gay man from Brazil who has suffered from lifelong clinical depression, explains it, facing his HIV diagnosis altered his entire life because it also forced him to confront the mental health problems and ingrained behavioral patterns that had inhibited him for much of his adult life.

“I became I think a better person. It was like a wake-up call for me, you know. Uh it changed my life, wanted or not. I mean, after all the years that I spent in denial, when I, when I decided to change and to take care of myself and try to understand and not to die, basically, not to give up, that’s when I started learning and then everything changed...I started facing the problems in a different way, trying to understand, you know, a lot of things that I, that before I was taking for granted Then I said, ‘Well no.’”
(Raul, 55 year old gay Latino man)

The Physical Domain: Adopting Habits of “Healthy Living”

Several interviewees, particularly those with histories of drug addiction, use words such as “turnaround” to refer to the changes they made in their lives after learning of their HIV status. For all of these interviewees, testing positive ushered a new commitment to sobriety into their lives. For example, Evette says of testing positive, “that was *my turnaround* because...there’s people in my life that I still seen...that was using, with the virus, it took them out, you know, it’d take you out fast.” Likewise, Valerie claims that testing positive spurred her to detox off methadone which she had been on for sixteen years, saying, “I really feel like *my own turnaround* in my own life should show people that regardless what you’re going through, your life is worth something.” William echoes this general theme, while varying the terminology somewhat; he says, “I changed my lifestyle, meaning I changed my promiscuous sexual ways, you know, and my doings my drugs. I stopped the drugging, I stopped the drinking, I like made *a whole about change*.”

Beyond ending behaviors such as drug use that they perceive to be unhealthy, many interviewees claim to have an increased interest in healthfulness in general as a result of their HIV diagnosis. As William puts it, “I had to make some healthy, sound choices for myself if I wanted to stay around and, ah, fight this life-threatening disease.”

This interest is commonly manifested in the physical domain; interviewees speak of adopting a range of new health behaviors after testing positive, from diet and exercise regimens and sleeping right, to herbal-based programs and acupuncture. Mary, a 31-year-old white heterosexual woman, says that because she is living with HIV she is much more conscious of her health; “you take care of your body more, you know, like yoga and all...and try to eat healthy.”

Just as frequently, this commitment to health is manifested on an emotional or mental level. As Raul says, “I’m treating myself better too...I come here [to GMHC] to a group and I go to a therapist. I’m taking antidepressants now, it’s helping me a lot.”

Many interviewees claim that since testing positive they pay greater attention to potential causes of “stress” in their lives and a commitment to stress-reduction. For example, when asked if his regular medical tests and statistics, such as his T-cell count, affect how he feels about himself, William replies,

“...for me, what works for me is acceptance. I accept the fact that on any given day that my T-cells could be high and my viral load could be low. But if I stress myself out, then it like shakes up everything and I become a mess. But as long as I stay focused and be consistent with my health, then everything levels out, you know...I try just easy does it, I try to take it easy. I keep it in a day, you know. Like I say, I try not to stress myself out, and that’s how I stay focused.”

The Interpersonal Domain: Increased Sociability

Victor, a 51 year old gay man who has been living with HIV for at least 15 years, cites both an increased sense of self-efficacy and a greater ease in social situations, fostered by his participation in AIDS-related organizations, as two beneficial consequences of living with HIV. Not only has surviving with the virus for so many years made him feel like a “stronger person”, being HIV positive also provided the impetus for his involvement in NYCAN, a volunteer-based HIV-AIDS political advocacy group under the aegis of GMHC’s Public Policy Department, through which he has made new friends and gained self-confidence. He says that, prior to testing positive,

“I wasn’t politically involved at all and I wasn’t very outgoing. I was very quiet and shy and some people would say, I guess, almost withdrawn, and through NYCAN I [have] now been on television, been interviewed by the press, speak in public quite frequently and really don’t think too much of it, except, wow, it’s really great that I can do this... Now I’ve realized through doing this work that you can’t always win and you don’t always make changes, but you can change the system and if you hang in there and keep pushing for things, you can change the system and you can make a difference, and that’s definitely helped me become more self-confident, you know, that I have been able to effect change.”
(Victor, 51 year old gay white man)

In fact, he continues, living with HIV has “...probably, believe it or not, changed the way I feel about myself in a positive, more positive way...just because I’ve survived and I’ve become an activist through this and...I’m doing things that I never thought I would do in my life. So it’s made me a stronger person.”

Reflecting similar themes, Rosie, a single Latina woman who lives with her HIV negative boyfriend, speaks of how her personality and self-concept have changed since her HIV diagnosis seven years ago. She says:

“...I feel like I have a lot to live for now, you know. I’m not so introverted...I’m more outgoing than I ever was, and I can’t work full-time, but I still work part-time, I still have a very active life, and I think that if I still had not gotten this diagnosis, I probably would have still been drinking too much and not enjoying my life.” (Rosie, 47 year old heterosexual Latina woman)

When asked how she was able to make these changes, she, too, cites the transformative impact of new social networks created through participation in AIDS-related social services, particular, in her case, the opportunity to forge connections with a community of other HIVers.

“I found that I needed to, to change my life. And the other thing is that I had joined a support group for women who were in recovery, women who were HIV and who were in recovery...and just being in that group and seeing all these women who had been long-term survivors, as I had been, who were still active, who were still relatively out there...it gave me inspiration, ‘cause when I ended up with PCP, I came out of the hospital and I had ten T-cells. And of course, I thought I was going to die and all that stuff, but I worked really hard at overcoming that attitude that, you know, I was going to die.”

HIV Diagnosis as a "Rite of Passage"

As will be demonstrated in the following section, interviewees' narratives of self-transformation can be analogized to Arnold van Gennep's conceptualization of "rites of passage" and Victor Turner's development of this model in his analysis of the "ritual process" (van Gennep, 1909; Turner, 1969). In particular, a parallel can be discerned between the transition from structure to anti-structure to renewed (and reworked) structure, that in van Gennep's claim, are fundamental to the rites of passage "which accompany every change of place, state, social position and age" (van Gennep quoted in Turner, 1969:94) and the basic plot structure of these narratives, a structure that is characterized by a narrative progression from a pre-diagnosis state of 'normal' daily life and established identity, to the traumatic event of HIV diagnosis, and finally, to the post-transformation state of reborn identity and renewed life. In many narrators' stories of self-transformation, an HIV diagnosis is presented as immediately effecting a "liminal period" of sorts, creating a narrative rupture in their ongoing life story as their routine existence and ordinary expectations are suddenly breached by the identity-altering interloper of HIV. However, just as Turner conceives of "liminality", in its traditional presentation, as a temporary state "betwixt and between" "normal modes of social action" (Turner, 1969:107 and 167) that is ultimately replaced by a return to structure – an altered, revitalized structure – so too do narrators find a way to repair the breach in their lives and identities brought on by an HIV diagnosis, reconceptualizing this event as an opportunity – both for crafting new lives and for reinventing themselves.

Initial Reactions to Testing Positive

Quite commonly, narrators of self-transformation stories describe their initial reaction to their HIV diagnosis as dominated by feelings of fear, despair and anger. By examining these narratives from the framework of Turner's model, the event of HIV diagnosis can be understood as initiating a cataclysmic break from normal "structure", as narrators' new knowledge of their HIV positive status propels a sudden, and unwelcome, disjuncture from the familiar routinized structure and ordinary emotional tenor of their lives.

William describes his first reaction to testing positive as one of "anger"; he elaborates,

"Anger, anger. Resentment, uh pain, pity, you know, I started pitying myself. Death sentence, you know? Not wanting to live, ready to end it all, what's the use of living now, you know? Yeah, I took it pretty hard at first."

Even for those interviewees who had strongly suspected that they were HIV-positive, the actual confirmation of their status can at first be difficult to handle. As Victor presents the experience,

"...I wasn't shocked since ...I just assumed at that time, after going through the little illnesses, losing my lover, I assumed that I was positive. It wasn't shocking, but I say it's still, when you first find out that you're positive, I call it the first year is, is like hell, the first year that you are positive, it's like it's the first thing you think of when you get up in the morning and the last thing you think of when you go to sleep at night."

According to Turner, “liminality is frequently likened to death” (Turner, 1969:95) – a feature that resonates strongly with Rosie’s experience of her first AIDS-related illness. After being simultaneously diagnosed with both HIV and AIDS while in the hospital with severe PCP pneumonia, Rosie initially felt as though she had lost her “will to live”. “I, I was scared”, she admits, “because I thought I was going to die right away, you know? I thought for sure I was going to die.”

Her description of the episode of social withdrawal and self-imposed isolation that she went through for the first several months after getting out of the hospital presents additional parallels to Turner’s representation of the liminal period. In Turner’s conceptualization, “liminality” is characterized by isolation and separation from the rest of society as “initiates” are physically and psychically cut off from their old identities and social roles and other members of society (Turner, 1969:125). Rosie’s description of this period of her life reflects these themes; as she puts it, “...since I had been so sick, I withdrew into myself and I would just sit for hours watching TV, not interacting with anybody. And you know, at that time I was living with my mother the first two or three months that I had just come out of the hospital...and it was creating a tension with her...”

This break from “structure”, or the normal routine of one’s daily life, can follow soon after one’s first HIV positive test, as the preceding examples illustrate; alternatively, it can be delayed until an individual begins to feel the deleterious physical effects of his or her infection. For instance, only in 1997, after he had been diagnosed HIV positive for

ten years, did John, a middle-aged cab driver, find his “can-do” attitude towards living with the virus slip away as he became increasingly fatigued. As he relates this period of his life:

“...because I had a work situation where I set my own schedule, I could go to work or not go to work, I was self-employed...I just started working less, working less hours on days that I worked, [working] harder and harder to make enough income to survive, and just feeling more fatigued. I just started to feel more and more isolated because if I, I would manage to work and had no energy for anything else. If I wasn't working, I was lying on the couch. I went out less, saw friends less, became more and more isolated.”
(John, 53 year old gay white man)

HIV Diagnosis as Rebirth

Another thematic element consistently articulated by interviewees in their narratives of self-transformation is the gradual abatement of this initial emotional reaction characterized by fear, anger and despair. In time, they come to think of their diagnosis as initiating a rebirth of sorts - an ironic reversal insofar as the very HIV diagnosis that many first understood as a “death sentence” is reinterpreted as an agent of new life.

Eventually, for example, with the assistance of a “health team” organized by her therapist that consisted of medical and mental health professionals as well as a few close friends and family members, Rosie was able to move from isolation to social connection, even surpassing her pre-HIV level of sociability.

“First of all”, she says, “I finally moved because I had the apartment [through DAS] and I didn’t move into it for like a month after I had it. I finally moved. I started to develop a friendship outside of the family. I started to go out more, a social life, I started to get a social life. I started to work on whether or not I wanted to have a love life...I had been working part-time prior to my going into the hospital, but I went back to work, and I did it with more enthusiasm. You know, tried to get more pleasure out of life...I chose not to be so closed-off with myself, you know, just to let other people impact on my life.”

Rosie’s testimony above suggests additional connections to Turner’s theory of the “ritual process” – specifically, a parallel with Turner’s conceptualization of the rebirth that follows the liminal phase as “initiates”, in his words, return to normal social “structure”. Critically however, in Turner’s theory (Turner 1969:94), individuals who have experienced this liminal break from the routine of their quotidian lives, do not assume the same position or role within that structure that they had previously occupied. Instead, having been fundamentally altered by the period of separation from their prior identities and from the rest of society that they have undergone, they emerge from the liminal phase as transformed individuals inhabiting new positions in society and holding altered perspectives on the world around them. Likewise, in their narratives of self-transformation, many interviewees speak of their emergence from the “liminal” phase of “isolation” and depression sparked by their HIV diagnosis as a period of renewal as they reconnect with society, but as profoundly different people forging new social connections with different people than they’d previously known – namely, with other HIV positive individuals they encounter within social contexts provided by AIDS organizations, such as support groups or volunteer organizations.

Evette explicitly contrasts her immediate response to learning she was HIV positive with her present point of view, after living with the virus for nearly ten years.

“At first,” she says, “I used to take it as a death wish, you know. And people used to say, Evette, shut up, don’t say that. But I take it as a second chance at life, you know? I’m here as an example to show people...how you can live and be like that [i.e., HIV positive].” (Evette, 47 year old bisexual African-American woman)

More implicitly, she also marks her initial understanding of her diagnosis as inappropriate by animating a group of fictive interlocutors (whom she tellingly refers to with the general and unspecified term “*people*”) who voice the dominant perspective, admonishing her for taking HIV as a “death wish”. By cloaking her description of her pre-transformed self with this evaluative overlay, Evette reveals her cognizance of, and orientation to, the dominant discourse’s attitudinal standards in terms of which she interprets her prior self. Moreover, the righteous indignation of her fictive interlocutors, suggests the extent to which, in Evette’s mind, at least, a fatalistic attitude toward HIV is taboo within the dominant discourse. Not surprisingly, then, she quickly makes clear that she has since dispensed with this ‘naïve’ point of view, coming to appreciate her diagnosis as “a second chance at life.” In so doing, she both presents her current self as in conformity with the normative model of HIVer identity, and illustrates the extent of her transformation.

In support of this interpretation is Evette’s use of the phrase “*death wish*”, which in the context of her surrounding discourse, can be interpreted as an idiosyncratic variation of

the expression “*AIDS is not a death sentence*”, one of the most well-known aphorisms of the dominant discourse on AIDS dating from the early years of the epidemic. This stereotyped maxim was widely reproduced in the 1980’s and early 1990’s, appearing in a multitude of contexts and textual formats, from advertisements sponsored by Federal and local Public Health Departments plastered on New York City buses and subway terminals, to informational pamphlets on HIV testing issued by nonprofit AIDS service agencies. While the use of this phrase in such public discursive contexts has diminished in the current post-protease era, it is remarkably common within the discourse of interviewees who relate accounts of self-transformation. The expression’s status as an easily recognizable token of “agency language” no doubt explains its popularity among narrators. As a result of its widespread use over the course of nearly two decades, the expression’s association with the institutional context of its origination – namely with the organizations of the “AIDS system” – has become fixed in the popular imagination, especially among fellow HIVers and affiliates of the “AIDS system”. Thus, narrators who reference aphorisms such as this in their speech – whether by means of verbatim replication or creative re-phrasing – exploit the indexical function of language to display their affiliation with the dominant discourse and with agency-espoused ideology.

A similar example is provided by William who, while admitting that he “took it [his HIV diagnosis] pretty hard at first,” makes clear that this was only,

“until I started to get educated with the fact that *this doesn’t have to be a death sentence* because they have a medication out on the market that can prolong my

life. That this is treatable, but not, you know, they haven't found a cure yet. So I started getting busy. I started getting involved, I started taking charge of my life, you know. I started with the medications and went to my support groups.”
(italics added)

Here he illustrates that once he received the proper information and got “*educated with the fact that this doesn't have to be a death sentence,*” his attitude towards his HIV positive status was transformed.

This segment of William's interview speech, in which his appropriation of the maxim “*AIDS is not a death sentence*” is paraphrased as “*this doesn't have to be a death sentence*”, demonstrates a more narrative strategy by which interviewees can use stereotyped phrases of “agency language” to demonstrate their alliance with dominant “AIDS system” ideology”. Here he attends to the referential content of the maxim to showing himself as embodying the principle it expresses. The actions he presents himself as engaging in subsequent to his reassessment of the meaning of being HIV positive – “*I started getting busy. I started getting involved, I started taking charge of my life, you know. I started with the medications and went to my support groups*” – provide a direct counter to the image of someone living under a “death sentence”.

On a broader level, narratives of self-transformation in general serve a similar function. In relating their movement from an initial reaction of fear, anger and hopelessness to an acceptance of HIV – even, in some cases, to the point of viewing their diagnoses as a “second chance at life” or a “blessing” – narrators' reinterpretations of their diagnoses are

concordant with the substantive content of this aphorism that is a central tenet of dominant discourse. Their narratives actually in effect act out this ideological principle; their testimony serves as confirmation that AIDS is indeed not a “death sentence”.

This analysis points to some significant psychological functions these narratives serve for HIVers. Most obviously, narratives of self-transformation re-interpret an experience typically understood as negative (both by mainstream society and by narrators’ in their “pre-transformed” incarnations) into an ultimately positive life event, as the frequently traumatic event of HIV diagnosis is re-fashioned into a motivating force and an opportunity for change.

Furthermore, in relating their accounts of testing positive and describing their immediate reactions to this news, clients characteristically construct their pre-transformed selves as passive “victims” of fate, objects of this tragic event that has been visited upon them, and powerless in the face of it. In contrast, narratives of self-transformation serve to re-position narrators within their own life stories, by presenting them as active agents who have regained control of their lives and are the architects of their own fate. Thus, these narratives, in their reification of self control and individual autonomy, both reflect and perpetuate a broader American ethos of individualism and self-reliance.

The Philosophy of “Empowerment”

The notion of “empowerment” may be considered the central defining feature of the dominant discourse’s model of the ‘proper’ HIVer. Thus, a key function of narratives of self-transformation is to demonstrate the narrator’s belief in and adherence to the principles of “empowerment” and his or her embodiment of “empowered” attitudes and behavior. Narrators demonstrate their adherence to this model using a variety of discursive strategies, which exploit multiple elements of linguistic structure. For the present analysis, I focus on three of these strategies. First, on the lexical or phrasal level, narrators may adopt and re-voice specific linguistic indices of “empowerment”, such as the word “empowerment” itself, and/or specific words or phrases closely associated with this philosophy. From the perspective of broader, sentence-level language structure and the referential content of speech, narrators may reproduce, in their interview discourse, characteristic themes associated with “empowerment”, displaying their affiliation with the philosophy by espousing its fundamental tenets. Finally, narrators can demonstrate their adherence to this model narratively, by portraying themselves enacting fundamental principles of “empowered” behavior or adopting characteristic “empowered” attitudes.

Valerie, a 38 year old waitress who lives in “scatter-site” housing for people with HIV/AIDS in Brooklyn, frames the “empowerment” she gained relative to her HIV status with giving her the motivation and determination to detox off methadone which she had

been on for almost sixteen years. As she explains it: “I guess along with the *empowerment over dealing with HIV issues came empowerment over my whole life.*”

(Valerie, 38 year old heterosexual white woman; italics added)

Thomas, a 45 year old man who is an extremely long-term survivor of HIV, having lived with the virus for at least 18 years, says the following about his choice of agencies for which to volunteer, “PWAC [People With AIDS Coalition] was to me really the appropriate place for me to go because it was an agency about *empowerment...*”

Later in his interview, he elaborates:

“PWAC had its mandate and its mandate was to *empower* the person living with the virus. And that’s what we mainly *did...* We *talked* about *empowerment*, we *explained* to people *how* to do things, we *showed* them, we *gave* them the phone numbers that they had to *call...*”

(Thomas, 45 year old heterosexual African-American man; italics added)

Several features of Thomas’s and Valerie’s language use in these segments are germane to the present analysis. Most salient is their direct use of the word “empowerment” and their explicit orientation to “empowerment” as a positive model for one’s behavior and attitude; their conscious awareness of “empowerment” as an ideal standard speaks to the prescriptive nature of this model. Indeed, Thomas and Valerie repeat the word “empowerment” multiple times – both within the single turns quoted above, and throughout the larger topical sections of the interview in which they are embedded. Furthermore, Thomas and Valerie each introduced the term and concept of

“empowerment” into the ongoing dialogue of their interviews¹⁷, a fact which suggests centrality of the construct to their self-concepts as “people living with HIV”. Also notable is the location of their introductions of the “empowerment” theme within the larger topical sequence of their interviews; they each begin to discuss the importance of “empowerment” in their lives just as the topic shifts to their experiences with AIDS service organizations, suggesting an intimate linkage between ideas of “empowerment” and agency participation in their minds. Finally, I point to Thomas’s use of lexical items connotative of key themes of “empowerment”. As will be discussed shortly, fundamental to the “empowerment” construct is an emphasis on the importance of “doing for oneself”. Reflecting this theme, Thomas articulates a string of action-oriented verbs – “empower”, “do”, “talk”, “explain”, “show”, “give” and “call” – within a relatively short stream of speech to describe what the concept means to him. Not only are these action verbs metaphorically symbolic of the key empowerment theme of pro-activity, by embedding them within the repetitive syntactic structure of “we” plus the past tense form of the verb (“*We talked* about empowerment, *we explained* to people how to do things, *we showed* them, *we gave* them the phone numbers they had to call...”), he lends particular force and drama to his words, giving the effect of modeling “empowered” behavior in his speech (see Tannen, 1989, on the functions of repetition in spoken discourse).

¹⁷ The notion of “empowerment” was not mentioned in any of my prepared interview questions, nor was I sufficiently familiar with the concept at the time these interviews took place to spontaneously interject it into my questions.

Knowledge = Power

As numerous interviewees attest, gaining information about the virus plays a major role in their ability to come to terms with their HIV status. Indeed, this equation of knowledge and information about HIV with power – both over the disease and over oneself – is a central tenet of the “empowerment” ideology. Information and knowledge are seen as powerful because they provide an HIVer with “choices”, “options” and “solutions”, to use words that reappear consistently throughout interviewees’ narratives of self-transformation. In essence, then, the power of knowledge and information within the framework of “empowerment” lies in their ability to enable action.

Thomas highlights his role as a dispenser of information to those in need in his discussion of his work on PWAC’s hotline, a service that distinguished itself from the plethora of AIDS hotlines by being staffed entirely by HIVers. He says, “You call in on the hotline from Fleatick, Alabama or some small town, where they don’t have any *information*, you get people the various *information*...” He reiterates this emphasis on the power of “information” a bit later in his interview while relating how he educated his family about the virus in the years after he was diagnosed (he was diagnosed in 1981, before the HIV test was available or the syndrome fully identified). Note that he repeats the word “information” three times within this brief stretch of speech. “But now they got more *information*, I send them *information* in the mail from the different magazines that put

out a newsline and stuff like that, I send them *information...*” (italics added in both quotations)

Roland, a 29 year old gay African-American who first tested positive a year and a half before his interview and now works as a “peer health specialist” at GMHC, reiterates this theme in discussing how he has come to grips with his diagnosis:

“...I just knew that for me, that’s what I had to do. I *had to learn as much about this as I possibly could...* because it made me feel more like *empowered...the knowledge is like key*, I mean, for like to make changes and do things and like *being informed is crucial*. If you’re going to be dealing with anything that’s like substantial in your life, *you have to know what you’re dealing with...* and then you have to just constantly be on top of things because it’s always changing.” (Roland, 29 year old gay African-American man)

Identity Confers Understanding

Another foundational theme of empowerment ideology is the idea that in an utterly crucial respect, being HIV-positive is essential to understanding the experiences of other HIVers – in essence, a belief that identity itself confers understanding. Ron and Thomas, both long-time volunteers and “peer” counselors for the New York City branch of the now-defunct People With AIDS Coalition (PWAC), attest to this belief in their evaluation of the vital importance of PWAC’s foundational model of using only HIV positive individuals to staff their hotline and write for their HIV/AIDS-focused monthly, *Newsline*. Ron describes his reaction to learning that the organization for which he had

been a devoted volunteer was folding and its “peer-run” hotline was being discontinued in these words:

“...I had been volunteering for years over at People With AIDS Coalition. On the hotline...And that was a hotline where people could call up and talk to somebody living with HIV and AIDS. Which is very different than most of the other hotlines...and then when they told me that the hotline was not going to be – you weren’t going to be able to disclose your sexual orientation or your HIV status, I said...I said there’s no – that’s the whole point of the hotline, calling up and talking to somebody with AIDS...when the hotline coordinator said to me...”These are the [new] guidelines...I said, “That means that your grandmother could sit here and answer the phone.” And he said, “Well, with the right training, anyone could do that.” I thought I’m outta here.”
(Ron, 46 year old gay white man)

Thomas echoes this sentiment in extolling *Newsline*’s unique virtues:

“You know why it’s the best magazine in the whole country? Because all the articles in the magazine, every last one of them, was written by a person that lives with the virus...There’s no other magazine in the United States that’s called an AIDS issue-oriented magazine that the articles [are all] written by a person that’s positive...”

Then, while elaborating on the value of the “peer” concept to PWAC’s hotline, Thomas indexes the dominant discourse by referencing the well-known phrase “You’re not alone” that was coined by the New York City AIDS organization Body Positive in the early years of the epidemic and has been much reproduced. He first quotes this phrase verbatim, then paraphrases it twice in providing specific examples of the ways in which being HIV positive can make an individual feel “alone”.

“so then people don’t think they’re so much alone anymore...*you’re not alone*, that’s the nice saying that Body Positive used. When you got the virus, sometimes *you just can’t help but feel that you’re alone*. You could be in here [GMHC], sitting up in the lunch room full of people eating lunch and laughing and joking, and it’s just *that feeling comes over you that you’re all alone*. Even though you know that you’re not.” (italics added)

The phrase “You’re Not Alone” is in fact the title of *Body Positive*’s “Creed” – a manifesto about living with HIV that was first published in their magazine in 1986 and stands as a foundational text of the “PWA Empowerment Movement”, reappearing in every subsequent issue to this day. The “Creed”, as reproduced in a recent issue of *Body Positive* begins with the words, “You Are Not Alone: There are more than 2 million of us in the United States. Don’t isolate yourselves,” and ends with the affirmation, “Just remember: those millions of people living successfully with HIV are people who’ve reached out to get the help they needed. Wherever you are, you can find support, or the means to create it. It just doesn’t make sense for us to face the same issues without helping each other out. We are not alone. And neither are you.” (*Body Positive*, September 2001: 7-8) The power of the statement “you are not alone” derives from the premise that identity itself confers understanding, from its implicit assumption that there are others who understand what you are going through because they are going through the same experience.

The “identity-based” service structure that is a feature of large ASOs such as GMHC mirrors this belief that only those who share the same “identity” can fully understand each other. GMHC offers support groups for highly specific categories of individuals,

such as “women who are living with HIV/AIDS and who are active alcohol or drug users”; “women who are living with HIV/AIDS and who have a past history of substance use”; “parents and caregivers who are living with HIV/AIDS and who have a past history of substance abuse”; “women in early recovery who are living with HIV/AIDS” and so forth¹⁸. Of course, which particular feature of an individual’s identity is relevant in any given context is highly variable; the fact all individuals necessarily embody countless “identities”, only a relatively fixed and predictable set of which are addressed by service organizations, not only presents a practical dilemma for identity-based services, but also reveals a fundamental paradox in the ideology upon which these services are based. Moreover, this type of organizational structure which literally separates clients according to gender and other characteristics may have the effect of reinforcing social divisions among clients.

Body Positive’s “Creed” is further relevant to the present analysis in the way it lays out not only the key themes of the “empowerment” ideology but also the central premise of narratives of self-transformation – namely the notion that an HIV diagnosis can be a “new beginning”. Consider, for example, the following passage, which resonates strongly with the themes voiced by so many HIVers in this study:

“Starting Over: One of the truths of testing HIV-positive is that once you know, you can **never not know** again... Your life will always be different now... You may find that many of the priorities in your life change rapidly... Many HIV-positive people have made huge changes in the way they live. Many have broken

¹⁸ These support groups are included in GMHC’s “Calendar of Events” for August 1999.

bad habits, such as drinking too much or smoking. Some have gotten out of bad relationships or quit jobs they hated. Facing the possibility of getting sick or dying has made many of our lives much better because it has made us take action in areas we have previously ignored or repeatedly put off. Mortality can be a great motivator.” (*Body Positive*, September 2001: 8; boldface in original)

The Model of the Empowered “PWA”

Fundamental to the ethos of “PWA Empowerment” is a belief in the supreme importance of “*doing for oneself*”, to borrow a phrase used repeatedly by Thomas in his interview. The ‘proper HIVer’, according to this model, is one who is self-reliant and responsible, who values action above all else and rejects passivity. This valuation of individual agency is directly linked to the belief in the power and utility of information that lies at the heart of the empowerment ideology; both are fueled by the underlying assumption that, armed with the appropriate knowledge, an HIV positive individual can and should – indeed must – *act* on this knowledge to make positive changes in his or her life, no matter how dire the circumstances may appear at first blush. An emphasis on “doing for oneself” is clearly evidenced in Body Positive’s institutional self-description: “Body Positive’s peer model of self-help offers information and support to help people make the best possible decisions to increase both the length and quality of their lives.” (*Body Positive*, September 2001: back cover)

Thomas illustrates this aspect of empowerment by way of the following vividly drawn scenario:

“...it became a problem for a long time, the people that were positive, that *they wasn't doing anything for themselves*. ‘Oh I got my benefits, I’m gonna to lay home, I’m gonna stay in my house, I’m only gonna leave my house when I have to go to the hospital. I’m gonna do my best to get the ambulette service. I’m gonna call God’s Love We Deliver, I’m not gonna cook. I’m gonna take the ambulette to the hospital, I’m not gonna take walks ‘cause I’m gonna die.’ That attitude was getting very, very pervasive....and I mean, it’s just hard for me to deal with that attitude. And I get a little bit aggravated... You know, sometimes I get tired, I’m having a problem with the medications now... My viral load is starting to go back up but *I’m not going to let it overwhelm me.*”

Note that here Thomas uses the narrative technique of “constructed dialogue” (Tannen, 1989:110) to animate a fictive foil – an apocryphal HIVer who is lazy and fatalistic, only wanting to receive services from a panoply of AIDS agencies while he lays at home in bed waiting to die. He then distinguishes this foil from himself using two distinct discursive strategies. First, he provides a meta-linguistic commentary about the foil he has just animated, explicitly stating his opposition to that approach towards living with HIV with the words, “ “it’s just hard for me to deal with that attitude. And I get a little bit aggravated.”, while making sure he doesn’t sound so harsh as to be uncaring or dictatorial (note his use of lexical mitigators such as “a little bit”, when his tone of voice sounds far more than “a little” aggravated!). Secondly, he illustrates his own contrasting approach to life with the virus in action by presenting an example of a difficulty he has recently experienced – “sometimes I get tired, I’m having a problem with the medications now” – and the way he chose to deal with it – “I’m not going to let it overwhelm me”. Whereas his foil embodies the fatalism of those HIVers who are not “doing anything for themselves”, he himself embodies the “empowered” attitude of those HIVers who do not let everyday setbacks “overwhelm” them.

This passage from Thomas's interview is also significant because it reveals that Narratives of Self-Transformation can function not just to construct HIVers own identities, but also to construct social divisions. Here Thomas establishes a division among HIVers on the basis of differing levels of adherence to "proper" "empowered" behavior and attitudes – in essence, differences in the extent to which they adhere to dominant discourse's image of the "proper" HIVer. He then uses this social division as a vehicle of identity construction – by contrasting himself with "them", the lazy, fatalistic HIVers, he firmly situates himself in the camp of "us", the "empowered" HIVers.

Closely related to this centralization of individual agency is a companion belief in the power of "positive thinking". To quote again from Body Positive's "Creed": "Your life does not have to be doom and gloom. It is possible to have a very positive attitude as a person living with HIV – millions are doing it right now – but it is much more difficult to get on with your life if you're trying to do it alone."

William, who identifies himself to me early in the interview as a "HIV Peer Educator/Substance Abuse Counselor" voices these themes in his response to my question about how he feels about his recent decision to go back to work. "I feel great", he says, "A little scared because, you know, anything can happen, but I'm not trying to go and think negative and all. It's about being positive, thinking positive and taking charge of my life today." In this short passage he paraphrases two stereotypical

expressions of “empowerment” ideology – namely, “*positive thinking*” and “*taking charge of [one’s] life*”. In fact, the use of such language is a dominant pattern throughout William’s entire interview and is no doubt closely related to his heavy involvement in AIDS service organizations as a client, hotline volunteer and peer educator, as well as his background in substance abuse counseling and 12-step ideology.

More specifically, the ideology of “empowerment” promotes a prescriptive model for HIVers’ health-related attitudes and behaviors, including their self-presentation within the healthcare setting, their interactions with medical professionals, and their attitude towards the acquisition of technical medical knowledge regarding HIV and its treatments. The governing principle from which the discrete components of this model derive is an absolute belief in the necessity and value of adopting a proactive approach to one’s medical treatment for HIV – an approach that is instantiated, for example, by an assertiveness in medical encounters and a commitment to being actively involved in one’s own treatment decisions instead of allowing one’s doctor to dictate the course of treatment, as well as the assiduous acquisition of relevant medical information prior to making such treatment decisions.

Another excerpt from Body Positive’s Creed illustrates this theme:

“Know this – you do not have to give up control of your life...[Arm] yourself with information and [decide] what is right for you...It is your life, your body, your health, and no matter how well-meaning your family, your friends, or your doctor may be, they have no right to take control of your life. Allow yourself to take time to decide what you want to do. Then go do it. (*Body Positive*, September 2001: 8)

Thomas explicitly articulates what this aspect of empowerment means to him:

“So this is another form of empowerment... We [the “peer” volunteers at PWAC] encourage people to take charge of living with the virus, we encourage people to talk to their doctors, we explain to them how to write up a list of questions... when we sponsored seminars or health fairs, we encouraged people to come out and get information. We encouraged people to write articles and share their experiences of living with the virus, dealing with their doctor, dealing with Kaposi’s Sarcoma, dealing with MAC, dealing with PML... with the magazine, with the hotline – we had the treatment education thing... we really worked on the key things, working with your case manager or getting your case manager to work for you, like they’re supposed to. How to deal with DAS and what steps you should take if you’re not getting your appropriate services...”

Ron, who introduces himself to me as a “forty-six year old gay man with AIDS”, and who has known of his HIV positive status since 1985, soon after the first antibody test became widely available, embodies the ideal of empowered behavior with his “stick-to-his guns” approach to dealing with persistent and pushy doctors. In the following passage, he relates a recent disagreement he had with his doctor:

“Well, the doctor, yesterday the doctor was going over some drugs that he might try to plug in, depending on what this genotype [test] shows, and one of them he mentioned was D4T, and I said, uh-uh-uh-uh... I had such horrible reactions to that medication...”

Where other patients may easily acquiesce to a doctor’s recommendations, Ron demonstrates that he is not afraid to strongly counter his doctor’s suggestions, and even has veto power over them.

In the following excerpt from his interview, John clearly reveals the extent to which “advocating for oneself” is considered to be a “preferred” and normative behavior within the world of AIDS services. He discusses his imminent plans to change doctors in order to demonstrate how much he has changed as a person since he became ill, went on disability and began involving himself nearly full-time in AIDS services.

“...[S]o at least I’ll see [my old doctor] one more time and, among all the other things we’ll discuss is, you know, what’s my transition going to be to another doctor and who will I choose – I won’t let them assign me. I want to know who the doctors are and I’ll choose. So, see how good I’ve become? (LAUGHS) You know, I’ve really gotten so that I really am advocating. Rather than like receding into the woodwork, I’m advocating for myself.”

John’s metadiscursive commentary on his own behavior, phrased first as the question “*So, see how good I’ve become?*” which is addressed to me, the interviewer and listener, and later as the evaluative statement “*I’m advocating for myself*”, shows him orienting to, and assessing his own behavior in terms of, a normative standard of behavior. According to this standard, “advocating for oneself”, being proactively involved in one’s own medical treatment and making decisions instead of allowing doctors or benefits bureaucrats make them, is “good”.

Cultivation of Expertise

Yet another manifestation of “empowerment” is represented by the phenomenon whereby some clients construct the identity of a “patient-expert” (*New York Times*, July 2, 2002: F7). Several interviewees, particularly those who are the staunchest adherents of the “empowerment” ideal, have become medical autodidacts as a way of grappling with the reality of their HIV status, immersing themselves in information about the virus itself and its various treatment modalities by, for example, conducting regular internet-based research from their home computers, reading the HIV-related literature produced by or offered free to clients of many ASOs, and mastering the technical jargon of AIDS medicine and policy.

In the following excerpt from his interview, Ron displays both his familiarity with highly specific medical knowledge about HIV and its treatments and his mastery of technical medical jargon:

R: “Well, now I’m on a combination and I just sat with my doctor yesterday and I said, “What, what should I do because the drugs that I’m on are not working, and should I stay on them and continue to develop more mutations in my virus, or should I just go off everything?” And he ordered a genotype test so we’re going to wait a month and see the results from that. See if there’s anything that they can plug in.

I: But you are taking something now?

R: Yeah, I’m taking one new protease inhibitor that I haven’t been exposed to, and then two old drugs that I have been – that I’ve had before.

I: So basically, you would wait for a new class?

R: Well, even a new class wouldn't help because when the NNRTI's came out, I went into the first one of those, so now I have resistance to everything in that category. So it's very tricky right now.

Two features of Ron's language use in this passage are worthy of mention in the present context. First, Ron constructs his relationship with his doctor as collaborative. He portrays himself as having a dialogic conversation with the medical expert in which he is comfortable asking his doctor difficult questions, questions his doctor cannot readily answer, but must order a test to investigate. His use of the pronoun "we" to reference his doctor and himself at a key juncture is also telling; he says "*we're* going to wait a month and see the results from that [genotype test]", the implication being that when the test results come back the two of them will evaluate them together. Thus, his choice of pronouns has the effect of portraying himself and his doctor as equals who work together as a team, making joint decisions about John's ongoing treatment. Secondly, in this stretch of discourse Ron displays a highly elaborated use of the technical medical register of pharmaceutical antiretroviral therapy. He is familiar with the different classes of anti-HIV medications, such as "protease inhibitors" and "NNRTI's" and the complexities involved in combining them, including the issue of viral cross-resistance and the use of different modalities of resistance testing.

A related phenomenon is the use of one's HIV status as the basis for vocational activities and positions. For example, a large number of narrators of self-transformations stories hold positions as "peer educators" for AIDS service organizations. Taking this

involvement one step further are interviewees such as Thomas and Arlene who have been able to parlay their HIV status and cultivation of HIV-related expertise into a vocation not only by working for AIDS institutions in the relatively low-status capacity of “peer”, but also by engaging in more prestigious agency-based activities including organizing and leading support groups, doing public speaking on AIDS, sitting on the boards of AIDS service organizations and acting as “community representatives” for government panels.

As Arlene says at the start of her interview, by way of introducing herself to me:

“Let me see, I go to Rivington Day Care Center, I come here [GMHC, as a client], I’m the co-chairman of the Advisory Board at the clinic I go to, Betances. I’m on the Advisory Committee Board at GMHC. I’m on the Advisory Board for the Lower East Side Harm [Center] (LAUGHS)”

Particularly notable is the fact that she introduces the topic of her agency involvement into her interview and supports it with this (partial) list of specific agencies and quasi-professional roles she holds without any prompting from me. The level of detail she provides suggests the centrality of agency involvement to her self-image and desired self-presentation as a person with HIV.

Thomas outlines a similarly heavy involvement in a host of AIDS-related agencies. In response to my very first interview question asking him to “tell me a little bit about yourself”, Thomas highlights his agency-based vocational roles:

“I’m an advocate for people living with AIDS. I was with an organization called People With AIDS Coalition of New York that closed about three months ago, so I’m presently with a newly-formed organization called Solutionz... On December 1st, 1997, I addressed the general body of the United Nations on World AIDS Day.”

As he elaborates on his experience addressing the U.N., he echoes the essential theme of self-transformation.

“As far as I was concerned, it went very, very well, and it was a milestone for me because prior to that I had – well, in 1985, I got into some serious troubles. I did some time in [prison], I actually just came home in 1996, so here’s a year later after being home, I’m addressing the General Assembly of the United Nations. So I mean, it did a lot for my self-esteem, okay? It did a lot for that. I also received the Mayor’s Volunteer Service Award I’m in contention now for the Governor’s Volunteer Service Award...”

Narratives of “Deferred” Transformation

Within my sample, narratives of “deferred” self-transformation are the most commonly used form; of those interviewees who use narratives of self-transformation, 62 percent use the “deferred” variant. Moreover, those interviewees who use the “deferred” variant are significantly likely to have histories of drug or alcohol use; 85 percent of those who use this variant are former substance users, as compared with 67 percent of all those who use narratives of self-transformation, and 68 percent of those within the overall sample.

The defining theme of this narrative variant is the centrality of a characteristic plot structure – namely, the existence of significant delay between an individual’s HIV diagnosis and his or her ultimate transformation – that is either entirely absent from, or backgrounded within “standard” narratives of self-transformation. What is particularly notable about such narratives is the extent to which this period of postponement, in which narrators are aware of their HIV status, yet continue on with their pre-HIV attitudes and patterns of behavior, is emphasized and elaborated on by interviewees.

Valerie speaks of a gradual change after testing positive in the late 1980’s while she was an IV heroin user; the difference between her “deferred” narrative and the “standard” form is one of degree – namely, the particularly long period of time that elapsed between her initial HIV diagnosis and her ultimate desire and commitment to change the way she was living. In addition, like most individuals who relate a story of “deferred”

transformation, she speaks of herself as being in a period of “*denial*” for some time after her initial HIV positive test, and even after she had this result confirmed with a second test a few years later.

“I think when [the HIV testing counselor] first told me, I was like really in denial about it, and I think I told myself that it must be a mistake and I just kind of forgot about it after that, and, um, and then I went tested – and got tested again, um a couple of years later...the first thing that I actually did about it was like in 19 – um, maybe ’92, ’93, started reading *POZ* magazine, *A & U* magazine, magazines geared to people that are HIV positive or that want to learn about it. After reading, reading like magazines with a lot of HIV-relative issues in it and, um, knowing that I had been a drug user, um, that’s what made – when I stopped, when I really wanted to stop using drugs, that’s when I said, well I’m going to make every aspect of my life better and I know that taking better care of myself will help me live longer dealing with HIV...and then I decided that I have to get the methadone out too, that even though I wasn’t using street drugs, being on the methadone program was still using drugs, it’s dependence on the drug. And I really feel like my own turnaround in my own life should show people that regardless what you’re going through, your life is worth something.”

In this passage, Valerie emphasizes the important role that reading texts of the dominant discourse played in sparking her transformation; in her case, this took the form of independently accessing and reading mainstream magazines written for an HIV positive audience, specifically *POZ* and *A&U*. Her life change, initiated her exposure to this HIV/AIDS literature, is sequential and progressive – after first giving up her use of street drugs, she then detoxes from methadone, deciding to “make every aspect of [her] life better”. In contrast to some other interviewees, she describes her decision to change the way she was living as independent and self-motivated; she alone is the agent of her life “turnaround”, acting without external pressure or influence from others.

In Arlene's case, nearly a decade elapsed between her initial suspicion that she might be infected, when the newborn baby girl she had just given birth to tested positive, and her official confirmation of her HIV status through testing:

“Well, I actually was diagnosed ever since '86 – I mean, not diagnosed. I found out that I had it in '86 because I had a child at that time that had the HIV and they told me to get tested, but I stayed in denial up until – I kept getting pneumonia about ninety, up until '94, and I was going in the hospital but I was never tested until I went to Mount Sinai, and one time, being sick and they asked me did I want to be tested. But I actually stayed in denial from '86 until I was actually tested. I guess I had to be tested...for it to become a reality to me.”

While she continued to use drugs for a period of time after testing positive, it is ultimately this official HIV diagnosis that she credits with starting her on a path towards “getting her life back together.” Within two years after this test, she had obtained her own apartment through the city's Division of AIDS Services and was clean.

A: “...at first I was still, like, getting high off of coke, you know, and stuff. I used to be a heroin shooter, you know, but I haven't done that in about ten years, but I started getting into crack, you know, and cocaine, and I was still like getting high, but ...I eventually got an apartment in '94 and that's when I really started getting my life, you know, back together again and started taking care of myself.”

I: “And do you think that the diagnosis had something to do with that?”

A: “Yes, definitely, 'cause I think if I wasn't diagnosed, I would probably be dead using drugs, you know, and I just didn't want to die out that way, especially at that time seeing how people died, how they looked, you know. It was just awful how they just dried up and withered away, and I just didn't want to go like that... And then I started liking the way I was living and, and taking care of myself, and then I just started wanting to do better.”

This “deferred” variant of narratives of self-transformation is not exclusive to those HIVers who have a history of serious drug use; interviewees’ self-transformations may be delayed for a variety of reasons. For instance, John feels that HIV had relatively little impact on his life or self-concept until, after living with the virus for more than ten years, he became too ill to continue working as a taxi driver and was forced to go on medical disability. It is at this point in his life that he locates his true transformation – a change that, not incidentally, was coincident with his first accessing AIDS-related services. When he initially became too fatigued to work, he grew despondent, assuming that with no way to support himself, suicide was the only option. As he describes this episode,

“...you can’t just tell everybody you know, family and friends, that you’re going to commit suicide when the money runs out, so I just started to pretend to everybody...I told everybody I had gone back to work...I literally pretended to everybody that I was living this life that I wasn’t living any longer, and I just started heading toward the suicide attempt, which I then made in February, and fortunately, thank God, I say today, it was not successful, ‘cause now I have a whole new life.”

However, his perspective on his future prospects completely changed when, after recovering from the suicide attempt, he came to GMHC for help and was awakened to the possibility of receiving disability benefits, for which he had had no idea he was eligible. As he puts it,

“...after the suicide attempt, then I made more attempts to get help and it worked out much better...with people that I contacted professionally, I got all the help I needed...It’s been a wonderful process, a supportive process in many ways...I mean, it’s incredible that only six months ago, I was trying to commit suicide, you know. I’m in a period of expansion where I am, instead of my normal, you know,

tendency to isolate, I go out every day...I have lunch at GMHC, I take these classes – when I'm at lunch, I actually, I talk to people who are strangers, you know, I make new friends!...This is wonderful. It's like, it's like a whole new life."

Transformation as Moral Rehabilitation

The moralizing aspect of narratives of self-transformation is especially marked in the "Deferred" variant, and is frequently expressed through a denigration of one's pre-HIV lifestyle and identity.

As Evette expresses it:

"I thank God now that uh that I'm HIV positive because the lifestyle that I was using...God gave me a second chance at life because when I was drugging, the things that I was doing, things that was happening in my life when I was drugging I wasn't paying no attention to, you know. Now, He put me here – that happened to me for a reason, you know, that's how I take it."

Later in the same turn, she is even more direct in her construction of a "lifestyle" of drug use as directly responsible, in a moral sense, for HIV, saying "most people that come up with the virus now is because of the lifestyle that they have lived, you know?"

William, too, has a sharply negative evaluation of his pre-HIV ways, attributing his HIV positive status to the totality of his former "lifestyle", to "the drinking and the partying

and the drugs and promiscuous sex since I was a kid”, even though he was never an IV drug user and is not sure how he contracted the virus.

In the following quotation, Arlene not only constructs HIV as a catalyst for life change, she also clearly demonstrates the extent to which such transformations can be value-laden. She, in effect, presents her life story as a parable, using it to shore up a moral framework in which health is an achievement amenable to conscious choice and force of will. Further, as in the ideology of the dominant discourse, the distinction between physical health and moral goodness is blurred – being “the best in shape” and being, simply, “the best” are one and the same thing.

I: “And do you think that getting an HIV diagnosis changed – over the time that it’s been – changed how you feel about yourself or your life?”

A: “Yes, it changed dramatically. It made me feel better about myself because I took it as if I had it, I might as well be proud and be the best at it! (LAUGHS) You know, like be the best in shape – be physically, you know, the best that I can be, in having it...But I say definitely I improved in thinking about myself and wanting to live and accomplish things...’cause I look better than the average one out there and I feel just as good and I can do everything that they can, you know. It might take an effect on my body, but as far as doing any activities, well I do have a slight lung infection, you know, from the pneumonia and stuff, and I smoke and that don't help, so I have a little respiratory problem. But that doesn't stop me from going if I want to, you know.”

The Role of Agency Involvement in Clients' Transformations

As alluded to in several of the interview passages presented above, another recurring theme within clients' narratives is the vital role played by AIDS service organizations in encouraging and effecting clients' self-transformations. ASOs not only function as a source of discourse, both textual and interactional, that present a model of the 'proper HIVer', as seen in Chapter 5, they also provide a social context and a physical location for the creation of new social ties with other HIVers. Several interviewees' explicitly attest to the essential importance of agency involvement in the crafting of their new identities. For example, in the following quote, David, a 46 year old gay white man, cites the importance of agency involvement in his new life as a person living with HIV, explaining how the Social Day Care Program at GMHC helped bring him out of one of the darkest periods of his life two and a half years earlier when he was newly-diagnosed with both HIV and full-blown AIDS, had recently ended a disastrous romantic relationship and had alienated himself from almost all of his friends.

"I started coming here [to GMHC] – I came here for help, really, because I knew I needed some sort of help, um, and I was so isolated and I came here and they set me up...they have a day social program here, which at the time I thought, oh God, what am I getting myself into? They suggested it might be good for me. And it was for people who were basically homeless or live in SROs, and at the time I had like an SRO situation, a five-floor walk-up, share the bathroom with like eight people. Life was a nightmare, you know...there was no stress or pressure in the program...and it was like people that really cared about one another. We were from all walks of life, but most of us had had some type of run-in with drugs or lovers or, you know, all kinds of situations with people...and all of us dealing with HIV and AIDS, so it was like a family."

Specifically, he says he gained two things from his participation in these client services at GMHC – a routinized structure to his day and somewhere to go to leave his dismal apartment, and integration into a community of fellow HIVers.

For certain narrators, specifically those who have experienced class and race oppression, who are likely to be ex-addicts and may have histories of homelessness and incarceration, testing positive and affiliating with AIDS-related agencies has afforded them their first opportunity to do meaningful work and to achieve positions of status in mainstream society. For instance, Edgar, a middle-aged African-American man who is the live-in boyfriend of Evette and who participated in a joint interview with her, explains how agency involvement has given him something to be “good” at, a forum in which to be successful. When asked if he feels that living with HIV has changed his outlook on life, he responds:

“It changed for the better because now I have something to strive for – staying alive. When I was using drugs and just running, just acting all crazy and being in denial, I wasn’t living for anything...And today, my mind is just cluttered with all kinds of stuff...Succeeding is real important to me because I never succeeded at anything else in my life except for going to get drugs...Now it’s like, when I go at something, I got to finish it.”
(Edgar, 45 year old bisexual African-American man)

In his next turn, he makes clear that being involved with the AIDS organization Exponents/Arrive, particularly taking their peer education training courses, has been a critical element of his transformation.

“Arrive...really opened up my mind to, um, passing on the information and the knowledge of harm reduction in an outreach type fashion...and it’s just, just broadened my horizon...I mean, I’ve learned so much in such a short period of time and then now, they seen that I was being active, so they gave me another opportunity to come back and learn some more, you know, ‘cause when I was a student, they saw my...interaction with other students and with staff, so they said, well okay, he look like he need to learn a little more, you know what I’m saying? ...And they’re putting me into the outreach department already – Monday I start.”

In fact, his and his girlfriend Evette’s experience at Arrive has been so positive that they now dream of beginning their own AIDS service organization someday.

Clients' Use of "Agency Language"

William uses multiple tokens of this register, and, as is common among interviewees who relate narratives of self-transformation, his use of these stereotyped phrases markedly increases in precisely the same portions of the interview in which he is explicitly discussing his involvement in AIDS service organizations. For example, as he is talking about his participation in a GMHC support group, he says that knowing other people who are also HIV positive is important "because it reinforces our support, you know, our recovery. That's important, yeah." He then continues, with no prompting, to say,

"it's important that people that are not positive also understand that this could happen to anybody, so you don't have to be infected, you can also be affected just knowing somebody who is infected, whether it's family member or a friend. This is a real serious epidemic that we have going on in the '90's, you know, so yeah, that's very important."

Here he diverges from his original point, about the importance of receiving emotional support from other HIV positive individuals, to address the importance of HIV/AIDS issues to the world at large. It is possible that he is saying this for my benefit, presuming that I am HIV negative, or he may be addressing some imputed future listener who might listen to the tape-recording of his interview someday. Whatever the case may be, the significance of his discourse for the present purposes lies in his replication of both the form and substance of elements of the "crisis construct" of AIDS. According to Rofes, this depiction of the AIDS epidemic as perpetually out-of-control, represented in such oft-quoted tag lines as "AIDS isn't over yet" and "People are still dying", is a central

tenet of hegemonic “AIDS system” discourse that serves AIDS institutions’ interests of self-perpetuation (Rofes, 1998:73-6). From this perspective, then, when William states that “this is real serious epidemic that we have going on in the ‘90’s”, he simultaneously reproduces agency ideology and displays his own identification with it.

In a section of her interview in which she is discussing her participation in numerous ASOs and related organizations, Arlene strings together several aphorisms characteristic of ASO discourse. She says her work as a peer outreach counselor for an HIV clinic on the Lower East Side is important to her,

“...because I think it helps other people that’s just starting out or just finding out that they are, you know HIV positive, and they need someone to be there to talk to them and let them see how well you’re doing *and you’re not dying from it, you’re living with it*, you know, and I think that’s important for people *because it’s not like it’s going away*. People thinking, oh they say they got a cure, and they got everybody fooled that...nobody was dying no more, but it is, *there are people dying and people still getting sick*, and it’s good to have somebody tell you that *as long as you take care of yourself, you know, you do have a chance in life as having a normal life.*”
(Arlene; italics added)

In fact, what is particularly interesting about this passage is the way Arlene seamlessly integrates stereotypical expressions of two competing ideologies of the dominant “AIDS system” discourse in her explanation of why her work as an HIV positive peer educator is important to her. On the one hand, she articulates popular expressions that construct HIV/AIDS as a “chronic manageable illness”. Early on in the passage cited above she says, “*you’re not dying from it, you’re living with it.*” Later in the same turn she repeats

this sentiment: “*as long as you take care of yourself...you do have a chance in life as having a normal life.*” However, sandwiched in between these statements are two characteristic tokens of the “crisis construct” of AIDS that appear to directly contradict her assertions in the surrounding discourse: “*it’s not like it’s going away*”, she says, “*there are people dying and people still getting sick.*” In order to make sense of this passage, it is necessary to look at Arlene’s larger topic and discursive goals, for it is not the substantive claims of these tokens of “agency language” that is central here, as much as their association with the AIDS institutional system. In this part of the interview, as she describes her full-time involvement, in multiple capacities from peer educator to Board representative, in numerous AIDS organizations, Arlene is attempting to portray herself as an agent of the institutional system that has played such a vital role in her construction of a new post-HIV identity. She demonstrates this affiliation discursively, both by articulating expressions that index the dominant discourse and by presenting herself as in line with its ideological tenets.

Thus, when portions of this the agency-approved ideology, particularly its moral relativism, come into conflict with her own personal value system, her identity construction is thrown into doubt. Immediately after the passage quoted above she says,

“...I don’t judge anybody – that’s what they teach you – but I don’t, I don’t think too highly of trying to bring a child in the world when you have this, you know, even though they have the medicines and this and that...I would never want to take a chance with nobody else’s life like that. God knows if I would have known that I had [HIV], you know, I would have never been in that situation.”

She ultimately resolves the ideological conflict by using another tenet of the dominant discourse – the behavioral canon of HIV Prevention – to support her position: “...and they tell you about protected sex and stuff, and you’re going around not having protected sex to get pregnant.”

Agency Involvement as Basis for Construction of “Us/Them” Divisions

As indicated earlier in this chapter, narratives of self-transformation can serve a dual function. On one level, they function to construct interviewees' new identities as HIV positive individuals, as the knowledge of their HIV status is integrated into an altered understanding of themselves. And at the same time, they function in many instances to construct a broad dichotomy between “good” and “bad” HIVers; several narrators situate themselves among the “good” HIVers by both presenting themselves as adhering to the ideological and moral precepts of the dominant discourse and by contrasting themselves with “other” HIVers who do not adhere to these same principles. HIVers' differing levels of agency involvement is one common basis for the construction of these “us/them” divisions among clients.

Significantly, the particular interviewees who evoke these “us/them” dichotomies tend, virtually without exception, to be those clients who are the most heavily involved in ASOs, often in “insider” capacities, such as volunteer or “peer” worker, in addition to the “client” role; have had the most positive experiences with ASO participation; are among the staunchest adherents of “empowerment” ideology; and articulate some of the most robust and elaborated narratives of self-transformation. This not only suggests that these individuals have internalized the precepts of the “dominant discourse” to the greatest extent, it also stands as further evidence of my broader claim that AIDS service institutions are directly implicated in clients' identity constructions as HIV positive

individuals, promoting the ideology of self-transformation that is at the root of so many interviewees' re-interpretations of their lives as HIV positive individuals.

For example, Victor criticizes those GMHC clients who are uninvolved in the AIDS advocacy work that is such a central part of his own life and whom he sees as passive and self-centered. In talking about his work for NYCAN, the GMHC-based advocacy group, he says,

“Getting people involved seems to be very difficult. I sometimes find it frustrating that there's not more people that are infected with HIV taking a part in doing volunteer work because I think it's really important. I think it's important for people that have HIV and AIDS *to put a face on the disease* so that people will get over the stereotypes or what they think people are like with the disease...it can be quite frustrating. Um, several time we've done petition signings in the dining room at GMHC and it just seems like people now seem to have an attitude...like I'm always lobbying for health care and people will say things like, “Well, I have Medicaid, I don't have to worry about people that have insurance.” And it almost seems like people are backing off and just saying, “Well, if I'm okay, I don't care about anybody else”...I just find lately that...more and more people just, as long as they're okay, they don't seem to care about other people, and I find that very frustrating.”

Similarly, Henry, a 31 year old gay African-American man who has been living with HIV for eleven years, denounces, as great length, the selfishness of many black male GMHC clients, as well as the ignorance and “denial” about HIV/AIDS he sees in the African-American gay male community in general. In the following portion of his interview, he constructs a dialogue between himself and an apocryphal representative of the type of GMHC client he feels predominate the agency:

“If GMHC were closing today and they asked the clients today if you have an hour, we could save the building if half of you stayed and filled out a questionnaire – “I got places to go, I got places to be, honey!” “You, you got benefits, you having nothing to fucking do all day, what’s wrong with you?” You think – “But the building – oh my God! They’re closing GMHC!” They’re not proactive about shit Nothing! Absolutely nothing! And I’m just speaking of people of color. I don’t know about nobody else. People of color, they don’t want to hear it. But they’re all here (LAUGHS) People who come to this place and – for lunch, you can count on your hand how many white people are here, you know, so I’m just like *the face of AIDS have changed.*”
(Henry, 31-year-old gay African-American man; italics added)

He also vilifies those GMHC clients, particularly other black gay men, who, in his mind, are concerned only with superficial matters, such as their own and others’ appearance, and do not want to “deal with the fact that they are HIV positive” by becoming involved in advocacy or taking part in research studies. As he says,

“Here at GMHC, anyone who’s got muscles, people are like, “Oh my – he’s at GMHC, he’s a client!” (WHISPERS) “He has AIDS too!” All of a sudden, he gets special preference, special client, sexuality preference. He gets kudos, a special gold star by his name because he’s cute and he looks like – you know, he doesn’t look like, he doesn’t look like AIDS so he has more points? So what point, what point do you not get about the AIDS? What point do you not get about it? The reality is, is that no matter how cute the face, that still is *the face of AIDS*, and you may not have a cute-ass face...but you got AIDS too.”
(italics added)

In these two quotes, Henry constructs proactivity around AIDS issues, as represented in the fictive scenario he relates by the willingness to sacrifice an hour of one’s time to fill out a questionnaire that could save GMHC, as a moral duty – one that is neglected by

most other African-American clients of the agency. In so doing, he presents himself as an adherent of the agency-supported ideology of “empowerment” – a fact that, in his mind, represents a marked contrast from the attitude of the majority of African-American GMHC clients.

One striking feature of both Victor’s and Henry’s discourse in all three of the passages above is their use of the phrase “*the face of AIDS*”, another well-known epigram of the AIDS institutional system; by indexing “agency language” in this way they are displaying their own affiliation with the ideology of the dominant discourse, and their affiliation with GMHC in particular, an identification that sets them apart from the lazy, self-obsessed GMHC clients they disdain.

In fact, “*the changing face of AIDS*” (which is intended to denote the shifting epidemiology of HIV in the U.S., as increasing numbers of heterosexuals, women, people of color and those living in conditions of poverty are infected with HIV) stands as one of the most stereotyped phrases associated with the AIDS system, and its use has spread well beyond this institutional arena, becoming widespread within the popular media and other contexts. For example, even in 1996, sociologists Adam and Sears use this phrase in the introduction to their book, *Experiencing HIV: Personal, Family, and Work Relationships*, stating that, “This project differs from much of the established AIDS literature by drawing respondents from outside the epicenters of the epidemic and by moving beyond the frequent concentration upon gay, white, male, and middle-class

subjects in order to follow *the changing face of AIDS...*" (Adam and Sears, 1996: xvii)

Adam and Sears' use of the phrase in an academic monograph is an example of its importation into a different cultural arena and a different textual genre, further illustrating its popularity.

Henry uses this phrase creatively in the two quotations cited above which are sequentially linked in his interview discourse. In the first passage, he says, "*the face of AIDS have changed*" – a paraphrase of the canonical form that retains the original meaning (he is uses it to refer to the growing number of African-American clients at GMHC). However, in this particular articulation of the phrase, he adds a creative twist; in saying "*the face of AIDS **have** changed*", he consciously – and ironically – uses a token of AAVE to highlight his own identity as a black man – the very group he has been assailing.

In the second passage from Henry's interview, he shifts the meaning of the stereotyped phrase, adapting it for his local discursive goals. As he critiques other black gay male GMHC clients for their superficiality, he uses a variation of the same phrase to emphasize his point that both good-looking and homely men can and do become infected with HIV, saying, "The reality is, is that no matter how cute the face, that still is *the face of AIDS*, and you may not have a cute-ass face...but you got AIDS too." While he uses this token of "agency language" for his own ends, he simultaneously indexes another central tenet of the dominant ideology – namely the truism that "AIDS does not discriminate", or in the words of *A & U: America's AIDS Magazine*, "we are all at risk."

Chapter 5. A Critical Appraisal of Narratives of Self-Transformation

Introduction

As I began to explore in Chapters 3 and 4, narratives of self-transformation are forms of identity construction that, on a personal level, serve certain affective, even existential, functions for HIVers who are clients of AIDS-related service agencies. As a discursive strategy, these narratives help establish an individual's identity as "HIV positive" by integrating this new identity feature into the individual's existing self-concept, while simultaneously integrating the momentous event of HIV diagnosis into his or her overall life story. This is accomplished through a re-imagining of one's HIV diagnosis as an opportunity for personal growth.

In addition to constructing and presenting a narrator's identity as a "person living with HIV or AIDS", narratives of self-transformation also index the dominant discourse of AIDS in order to position the narrator's identity vis-à-vis the discourse's normative model of the "proper" HIVer. This juxtaposition serves the ultimate purpose of these narratives – namely, self-reinvention. By presenting their transformed identities as conforming to the dictates of the normative model, narratively illustrating the ways in which their post-HIV selves embody the ideals of "empowerment", clean living, healthfulness, self-reliance and a motivation to learn about HIV disease and its standard,

accepted modes of treatment, narrators recreate themselves according to the values of mainstream society, thereby asserting their identity as moral beings.

The present chapter will elaborate on these functions in order to critically evaluate the effects of narratives of self-transformation on individual HIVers, as well as the potential ramifications of these narratives for power relations beyond the social world of the ASO. More specifically, this chapter addresses two central issues. The first concerns the potential impact of the use of narratives of self-transformation on narrators' lived reality and self-image. Although interviewees consistently relate these narratives in an overtly upbeat manner, portraying their transformations as decided improvements on their prior identities, might there be any negative consequences resulting from this mode of identity construction that are less attended to, or even dismissed, by narrators within the social context of the research interview?

Second, I attend to questions of the socially organized use of narratives of self-transformation (to the extent this can be inferred from the limited size of my sample), expanding on my preliminary treatment of this issue in the prior chapter. Which ASO clients, in particular, are likely to adopt narratives of self-transformation? Are the identities HIVers constitute and express through these narratives equally available and attractive to all agency clients? If not, then what perspectives do these narratives fail to represent, and which HIVers' voices are silent in these stories of self-renewal?

Before proceeding, I present a brief note about the analytic methods employed in this chapter. In order to assess the efficacy, potential consequences, and social patterning of narratives of self-transformation, I have employed three analytic strategies (although not necessarily in the strictly linear order in which they are presented here). The first strategy involves an examination of the discourse of the subgroup of interviewees who articulate narratives of self-transformation with the purpose of attending to points of conflict, areas of ambivalence or inconsistencies in an individual narrator's self-presentation that might be indicative of fundamental problems inherent in this mode of identity construction. The second strategy is comparative in a straightforward sense, geared towards the discernment of systematic differences in the interview discourse of narrators versus non-narrators¹⁹. Finally, while I am aware that the small size of my sample of interviewees, as well as the nature of my data collection techniques and analytic methods, precludes the assertion of definitive conclusions or broad claims regarding HIV-positive ASO clients in New York City in general, I do believe that the social and discursive patterns evidenced in the language use of these interviewees may be suggestive of significant trends within this larger community. For this reason, then, I have also made limited use of

¹⁹ While the analytic strategies listed above are theoretically distinguishable, in practice I found them (especially the first two) to be interrelated and overlapping facets of a more holistic interpretive process, elements of which, no doubt occurred below the level of my conscious awareness. Since most of the resulting analyses presented in this section – indeed, in the text as a whole – emerged from a combination of these strategies, I have opted not to explicitly link particular theoretical arguments with any particular analytic technique within the actual text. I mention these distinctions here merely in a modest attempt to explicate my methods as fully and accurately as am able, and is practicable in the present context.

simple quantitative techniques by, for example, comparing the number and proportion of interviewees who use particular discursive strategies or forms of identity construction.

Functions of Narratives of Self-Transformation for the HIV Positive Individual

In order to assess the effects of narratives of self-transformation, it is first necessary to consider what the use of these narratives “do” for those individuals who articulate them. Beyond the function of constructing one’s identity as a “person living with HIV or AIDS”, what needs do they fulfill on a personal level? While some basic functions of these narratives have already been addressed in Chapter 4, my present goal is to elaborate on these functions in greater depth, so as to provide a basis for my critique that follows.

The social interactionism of Erving Goffman, particularly as presented in *Stigma* (1963), his trenchant analysis of the social dilemmas faced by “stigmatized individuals” and the interactional strategies by which such “discredited” persons manage both their own identities and the interpersonal “trouble” that may be occasioned by their condition, provides a useful framework for understanding HIVers narratives of self-transformation. Although published in 1963, his disquisition on the “...management of spoiled identity...” contains remarkable parallels to the situation of HIV positive individuals in the U.S. at the turn of the millenium. Thus, in the discussion that follows, I outline some key insights Goffman’s conceptualization of “stigma” can lend to an interpretation of narratives of self-transformation with an eye towards the functions served by this discursive form for the individual narrator.

From a Goffmanesque perspective narratives of self-transformation can be considered forms of “identity management” in which personal information is manipulated through its narrativization. Specifically, they may be analogized to Goffman’s explication of the various techniques of “information control” (1963: 91) used by “deviants” to “manage” their “spoiled identities” by, for example, concealing the stigmatizing attribute in order to “pass” as a “normal”, or disguising the shameful attribute as some other, assumedly less disgraceful, condition. In the specific instance of narratives of self-transformation, the “information management” purpose served by these narratives is not the concealment the stigmatizing condition itself – the narrators’ HIV positive status – but, rather, the management of other elements of personal information directly associated with the narrator’s HIV status.²⁰

Instead of representing interviewees’ attempts at managing information towards the goal of “passing” as a “normal” (or a “negatives” in the context of HIV/AIDS), these particular discursive forms are ‘meta-narratives’ in the sense that they are stories *about* narrators’ attempts to manage, or come to terms with, the stigmatizing condition represented by their HIV diagnosis.

This points to critical aspect of HIV as a stigmatizing condition – namely, the fact that in the social a world of an HIV positive individual, there is more to manage than one’s HIV

²⁰ Due to the particular context of their telling – a research interview conducted on the premises of an AIDS service organization – a narrator’s HIV status was already known to

positive status alone. Attendant upon an HIV positive status are multiple layers of potentially stigmatizing information which must be managed and managed differently in different social contexts. These multiple component “attributes” that emanate from the ‘master attribute’ can function as additional sources of stigma beyond the serostatus itself. These potential sources of stigma include, for example, the means by which one was infected with the virus; the historical point in time of one’s seroconversion (which can be alternatively framed as the length of time one has been infected); and the nature of one’s current sexual practices - most saliently, their level of “safety”, as well as the identity, particularly the serostatus, of one’s current sexual partners. As Goffman notes, there is an intimate connection between stigma and morality; stigmatizing attributes – which may range from physical deformities to mental illness, to (certain) addictions and sexual “deviance”, to name just a few – are systematically conflated with moral defects. From the dominant point of view of society’s “normals”, to bear a stigmatizing condition is to be morally suspect.

me prior to the interaction and, in many cases, prior to our first face-to-face meeting; indeed, this knowledge provided the explicit rationale for and topic of our interaction.

Personal Responsibility

A significant source of stigma surrounding an HIV positive status derives from the dominant discourse's conceptualization of "personal responsibility." An important point to emphasize is the historical evolution of the nature of the stigma attached to HIV and AIDS; the specific source of this stigma has gradually shifted over the past 20 years since AIDS was first recognized as a syndrome – a fact that reflects and supports Goffman's assertion of the contextually dependent nature of social stigma. At the current historical moment in American culture, the notion of "personal responsibility" lies at the heart of the stigma surrounding HIV diagnosis.

According to the dominant discourse of AIDS, as well as the dominant ethos of American culture, one's identity as a moral person fundamentally depends on one's willingness to accept "personal responsibility" for certain hardships, tragedies and other difficult events that may occur in one's life. HIV infection is firmly entrenched within that category of events for which "personal responsibility" must be assigned; typically this responsibility is assumed by the infectee, except in those instances in which one has a legitimate "out", such as the construction of oneself as an "innocent victim" – a strategy which will be explored later in this chapter. The notion of "personal responsibility" is particularly central to the dominant discourse of HIV prevention, according to which "protecting oneself" through the use of condoms is a matter of "personal responsibility" that is an absolute and unquestionable necessity for those "at risk", or engaging in "risky" activities

– two categories that have fuzzy boundaries (as science has, to date, been unable to adequately define the risk of HIV infection attached to certain “unprotected” sexual acts – most notably, oral sex) and must, therefore, be defined “on the ground” by individuals in specific circumstances. Nonetheless, should one fail to define these categories adequately, or worse, knowingly court the risk of HIV infection by consciously flouting the behavioral dictates of modern HIV prevention, and consequently becomes infected with HIV today, when everyone “should know better”, one is presumed guilty of a failure of “personal responsibility.” (Note, too, that the temporal boundary at which point “one should know better” than to fail to protect oneself from HIV is just as fuzzily defined as that of “risk.”)

Narratives of self-transformation provide a way for individuals to simultaneously accept “personal responsibility” for their HIV infection and distance themselves from this culpability, as the “blame” for one’s HIV infection may be laid upon a past version of oneself that, as the narratives relate, the narrating self has moved beyond. The “bad” past self is, then, a discursively constructed alter-ego whose function is to shoulder the blame for an individual’s failure to comply with the dictates of the dominant moral economy of HIV, thus allowing the transformed “new” self that is constituted through the same narrative means, to disown this guilt and to reclaim a moral identity.

Of further relevance to to narratives of self-transformation is Goffman’s description of “voluntary disclosure” – which he presents as one strategy for managing a stigmatized identity. As Goffman explains, this particular technique of information control “allows

the individual to forego all the others.” By “voluntarily disclos[ing] himself,” he can “radically transform...his situation from that of an individual with information to manage to that of an individual with uneasy social situations to manage.” He further notes that such an individual “can come to feel that he should be above passing, that if he accepts himself and respects himself he will feel no need to conceal his failing.” (1963: 100; 101). Narratives of self-transformation do something similar – they represent an attempt to reclaim the stigmatized attribute of an HIV positive status, to divorce it from its dominant meaning, a meaning that necessarily derives from the perspective of “normals”, and represent it, from an ostensibly “in-group” point of view, as a positive attribute.

For many individuals, particularly ex-drug users, the stigma attendant upon an HIV diagnosis is compounded by the fact that their identities were already “spoiled” by the presence of one or more “stigmatizing” attributes prior to their assumption of an HIV positive identity.

As was noted in previous chapter, narratives of self-transformation are articulated, in large measure, by two groups of individuals within my sample of interviewees – gay white men and heterosexuals, mostly African-American and Latino, with histories of past drug addiction. This pattern raises the possibility that both gayness, “otherness” due to sexual identity, and a history of drug use, which is itself associated with poverty and racial “otherness”, can function as driving sources of stigma for narrators with an HIV diagnosis serving to underscore, and make public, this *a priori* lack of conformity with

societal norms of “preferred” behavior. However, there is a crucial difference between the narratives of self-transformation of the gay men in my sample and the former addicts that complicates this argument. The individuals with histories of drug abuse explicitly repudiate that behavior and prior identity; indeed, their narratives of self-transformation are efforts to craft a new identity. In contrast, none of the gay men who articulate narratives of self-transformation express discontent with a gay identity; their narratives are not “about” sexual identity at all, but center on other aspects of identity.

To briefly reprise a theme addressed in Chapter 4, narratives of self-transformation, in a general sense, also serve to endow HIV with a purpose, a reason for being in individuals’ lives; an HIV diagnosis is thereby rationalized, as opposed to seeming random and meaningless.

Ochs and Capps address this function in their discussion of personal narratives; they speak of the function of narrative in general to “make sense of experience”, to “impose order on disconnected events”(1996: 19) which, in the context of HIV/AIDS, is relevant to the often unexpected intrusion of HIV into interviewees’ lives, a disturbing event for which, as most interviewees attest, they have no precedent of an equivalent stature in their lives. This lack of a viable personal model for integrating their diagnosis into a cohesive life story provides an opening for the dominant ideology espoused by ASOs which offers a ‘ready-made’ interpretive framework through which they can find meaning in adversity.

What is more, HIV serves a positive function in their lives according to this construct, becoming a vehicle for the re-invention of the self, for “personal growth”. Since the dominant discourse both sanctions the ideology and narrative construct of “self-transformation” itself, as well as providing a model for the new, transformed identity that is the ultimate goal and product of this transformation, another salient function of these narratives is their ability to re-make individuals’ identities as HIVers in the model of the moral dictates and behavioral standards of the dominant discourse. Furthermore, for some individuals, narratives of self-transformation function as vehicles for a more generalized identity reformation; in these cases, as was illustrated by several narrators in the previous chapter, the theme of self-transformation is interpreted in more personal terms, as narrators speak of overcoming longstanding personality traits they viewed as deficits, by for example, becoming more outgoing or self-confident

My ultimate conclusion is that narratives of self-transformation serve multiple functions – they can serve different functions for different HIVers, and they can also serve multiple functions simultaneously for a single individual. For certain individuals, these narratives represent an attempt to counter the stigma resulting from their failure to comply with the behavioral dictates of “personal responsibility” as inscribed in the dominant discourse of AIDS, and in particular, the regnant model of HIV Prevention, by providing an accounting for this behavior in an attempt to justify it. While for others, they provide a way of attempting to overcome an identity that is already stigmatized prior to the event of HIV diagnosis.

The fact that the use of narratives of self-transformation is so widespread in my sample, even among those without personal histories that are a source of great stigma and personal shame, is a testament to the dominance of the self-transformation trope within the dominant discourse of HIV/AIDS, as well as in American culture in general. Moreover, it reveals a crucial aspect of the ideology that undergirds this trope – namely, that no identity is ever complete or good enough, but rather, all identities demand continual re-working. Although one can never arrive at a state of perfect being, one must nevertheless always strive for self-improvement - this is the lure of the model and the source of its universal applicability. Since it is the very nature of the model to which we aspire to change over time, we are assured of never reaching a state of complete transformation; instead, it is our lot to be ever approaching, yet always falling short of the mark.

Problems and Limitations with Narratives of Self-Transformation as Modes of Identity Construction

Following from the above discussion, the goal of this section is to interrogate the efficacy of these narratives of self-transformation in terms of the functions delineated above, as well as to consider other potential consequences of their use. How might the use of these narratives impact HIVers' lived experience and sense of self-worth?

Are the ideologies upon which clients construct transformed identities in these narratives as plainly beneficent as the narrators in my sample present them to be, and are the transformations they speak of as salutary in their effects as they are overtly portrayed by interviewees? Might there be any less salubrious consequences resulting from the particular form of identity construction effected in narratives of self-transformation, an interpretation of one's life and self in which one's HIV status is granted a pivotal and determining role, consequences that are backgrounded by narrators in their attempt to portray themselves in the most positive light? Is it possible to discern ambiguities, inconsistencies, or points of ambivalence in clients' interview discourse that suggest alternative or additional interpretations of these narratives?

Ultimately, I propose that in spite of the apparent affective and social benefits that may derive from conceptualizing one's life story and identity as an HIV positive individual through the prism of "self-transformation", there are also several reasons to be skeptical of the salutary effects of this construction.

Retrospective Re-interpretation of One's Life & Denigration of One's Past Lifestyle and Identity

One potential problem derives from the retrospective re-interpretation of one's life history that is fundamental to all narratives of self-transformation, but is especially dramatic in the case of individuals whose personal histories are marked by particular stigmatized behaviors, such as drug use, sex work, or sexual promiscuity.

For all narrators, the articulation of a narrative of self-transformation requires a re-assessment of one's pre-HIV existence and subjectivity from a *post hoc* interpretive perspective, as the transformed, narrating self revives a prior self, evaluating it from a 'more enlightened' point of view. As discussed in Chapter 4, through narratives of self-transformation, HIVers not only construct new identities as "people with HIV or AIDS" but also shape these identities in reference to both the actual events of their lives and the dominant discourse's normative standard for HIVer identity. Thus, in relating a narrative of self-transformation, an individual uses the event of HIV diagnosis as an opportunity to reinvent himself according to mainstream social values, reevaluating his old life from the perspective of the dominant ideology in order to cast it off, or distance himself from it.

For HIVers with particular stigmatized identities or past behaviors to "compensate for", the process, and the problems attendant upon it, is similar, but more acute. This process of reevaluation presents particular challenges for these HIVers, since conforming one's

identity to the dominant discourse's idealized vision requires the scaling of a significant narrative hurdle. Since past behaviors such as drug addiction and promiscuous sex, are not only stigmatized from the perspective of mainstream mores, but are also viewed as directly responsible for one's HIV infection, the assumption of a transformed demands an accounting for, or a justification of, the moral culpability inherent in these identities.

What is the potential cost of this separation from one's past? With regard to all narrators of self-transformation stories, we can ask: What is the ultimate psychic cost of dissociating oneself from one's own history? And with regard to those narrators with pre-existing stigma (who, for the most part, articulate "deferred" narratives) we can ask: What are the phenomenological repercussions of this derogation of one's pre-diagnosis life history? While narratives of self-transformation have the seemingly salutary effect of liberating individuals from the stigma attached to their "bad" past behaviors and selves, this liberation comes at the expense of a renunciation and a vilification of one's prior life history and identity – in essence a form of self-abnegation.

Beyond the potential psychological costs, this narrative process may extract a social cost. In a general sense, this denigration of one's past self implies a denigration of others who resemble that past self – which may have implications for social relations among HIVers and ASO clients, possibly encouraging social prejudice. With respect to a narrator's real-world social relations, renouncing one's past "lifestyle" typically entails a renunciation of those individuals and social networks one associates with that lifestyle, individuals

who are morally tainted by virtue of their association with the stigmatized behavior.²¹

As was explicated in Chapter 4, a central feature of many narrators' self-transformations is a heightened level of sociability and an expansion of one's social network that is fostered by AIDS service institutions. Thus, the adoption of a new transformed self may entail the severing of old social ties; as narrators adopt a new community of fellow HIVers encountered in the agency setting, they may dispense with all those who figured in that past.

Implicit in this retrospective re-interpretation of one's life history upon which narratives of self-transformation are constructed, and most particularly, in the denigration of one's 'bad' past self that forms the cornerstone of those narratives articulated by former drug users, are two fundamental ideological principles which are shared by both the dominant discourse of AIDS and American popular discourse more generally. The first is a reflexive personalization or psychologization of individual problems. For instance, as seen in the excerpts of interviewees' discourse presented in Chapter 4, narrators of "deferred" accounts of self-transformation characteristically attribute their HIV positive

²¹ This theme derives from 12-step ideology which explicitly dictates the avoidance of all "people, places and things" associated with the addictive behavior. Indeed, the whole concept of "self-transformation" bears many parallels to the ideology of "recovery". The thematic similarities between the dominant AIDS system discourse no doubt reflects mutual influence across these institutional domains; indeed, in many respects, one can conceptualize a the institutional arenas of drug treatment, AIDS services and social services more generally shared ideology.

status to a dissolute “lifestyle”, since the behaviors in which they had engaged prior to their transformation provided the route of transmission for HIV. Further, this ‘bad’ past behavior is typically construed by the narrating self, in her transformed guise, as symptomatic of a ‘bad’ past self. In this manner, narrators understand their troubles as resulting solely from their failures as individuals, their character flaws and wayward lifestyles, as opposed to the structural conditions, such as poverty, that allow these problems to occur. The ideology of “personal responsibility” which, crucially, is the foundational principle of widely popular 12-step programs, as well as modern HIV Prevention, is a significant source of this tendency to locate problems in the individual. The fact that this ideology is shared by the AIDS service industry, self-help movements and most modern drug treatment modalities reveals the extent of its dominance in modern American culture. Thus, the effect of these narratives, on the societal level, is to reproduce dominant ideology, and with it, hegemonic relations of domination and subordination.

The Fragility of Physical Health as a Basis for Self-Worth

Another issue raised by the widespread use of narratives of self-transformation derives from the dominant discourse's pervasive emphasis on the vital importance of physical health and its equation of health with moral goodness - an ideology that is also a feature of American popular discourse more generally.

As has been discussed in Chapters 3 and 4, many components of the dominant discourse's model of the "proper" HIVer establish norms for health-related behaviors, constructing, for example, the adoption of habits of "healthy living" and the proper "adherence" to antiviral drug regimens as compulsory and expected of all HIVers.

While this emphasis can certainly present difficulties for all HIVers, regardless of their stance vis-a-vis the trope of self-transformation, it poses a particular problem for narrators, many of whom base their positive self-image on their ability to meet these demands. For example, in the following passage, Thomas presents himself as a model patient by emphasizing his vigilant adherence to his combination therapy.

"I'm taking my medication every day. If I didn't take it every day, then I couldn't say this, because a lot of times, people say that but they don't take their medication daily. I take my medication every day, nine o'clock in the morning, nine o'clock at night, ten o'clock I take my Sustiva, every single day. I don't care where I'm at, I'm going to take my medication. I don't give a damn who sees me, I'm going to take my medication if I've got to take my medication."

Similarly, many other narrators cite their lab results – typically their viral load and CD4, or T-cell, counts – as unequivocal evidence of their "good" behavior.

However, there is an obvious fragility inherent in basing one's identity as a worthy and virtuous individual upon medical measures of physical health which are, by the very nature of HIV disease, labile – or upon one's ability to perfectly adhere to complex and toxic pharmaceutical regimens. What happens to this self-concept if one's health fails simply as a result of the predictable disease progression? Or if an HIVer who sees himself as a “responsible” patient, with an unimpeachable history of adherence, “slips”? Will these be occasions for self-reprobatation? A close examination of interviewees' discourse suggests that this is not only possible, but a common problem. In several clients' interviews, cracks are discernable just beneath the surface of their “empowered” self-presentations. Even among those individuals who appear to be the most exemplary embodiments of self-transformation, and whose lives, as presented in their interview discourse, would seem to demonstrate the potential success of self-transformation as a principle for organizing one's life, there is frequently ambivalence around the issues of medication and standardized measures of HIVers' health.

Thomas first hints at these issues as he is speculating on how the history of AIDS will be recorded. He says,

“So I'm curious how they put this down in future years. They're going to have to put down, they're going to have to put down the virus, they're going to have to put down the protease inhibitors now. People started making it back from really, really bad conditions. And they're going to have to put down the other things happening to people... so I'm wondering how do they put this down now? How

do they do this in fifty or sixty years? And the thing is that, one of the main reasons why I still do peer education and I still go out is because I know that people now, when they become positive, are more than likely going to be resistant to most of the medications.”

He then admits that he himself is experiencing problems with viral resistance; despite his best efforts to take his medication religiously, he finds himself running out of treatment options after his virus builds up resistance to medication after medication. As he explains it,

“...ddI failed, ddI failed for me. I didn’t fail ddI. I took it every time I was supposed to take it. 3TC failed for me, I didn’t fail 3TC, I took it every time I was supposed to take it. Uh, AZT failed for me...”

In this passage he creatively transposes the standard construction of the dominant medical parlance according to which a patient is considered to have “failed” a medication if taking the drug does not produce the desired and expected response, as measured by T-cell count and viral load. By insisting that ddI, 3TC and AZT failed *him*, not vice versa, he issues a metadiscursive commentary on the dominant medical paradigm that encodes a preference for drugs over people.

Thomas’s critique hints at the instability of a transformed identity that is predicated upon one’s compliance with normative health behaviors, particularly one’s level of adherence to combination antiviral therapy. Since the standardized measures of T-cell count and viral load are widely, and simplistically, understood to be indicative of an individual’s compliance with a medication regimen, by both doctors and patients alike, it is likely that an individual will be held personally responsible for medication failure.

Substantiation for this claim is provided by Arlene, whose self-presentation as a protease inhibitor 'success story' evinces increasingly wide fissures over the course of her interview. Early on she uses her adherence behavior as support for her construction of a responsible and empowered new identity which she contrasts with her pre-HIV identity as a homeless drug addict. For instance, she says that after finally confirming the HIV positive status she had long suspected, "I started taking vitamins and started taking my protease inhibitors, you know, and like religiously, I take my medication." Later in the interview, however, she complicates this resolutely positive image, saying,

"Well, the Crixivan [a protease inhibitor] had done wonders for my T-cells and viral load, but it just, um, I just got the side effects of the fatty tissues and uh and uh diabetes that they didn't know that that happened..."

Moreover, she blames herself, at least in part, for these recent problems, noting that

"actually it might have been my fault staying on it so long...because it was working so well and everybody was talking about how hard the time they had...so I was scared of any other change because you always hear about this medication with these side effects."

“Anti-Transformation ” Narratives

Speaking of narrative in general, Ochs and Capps note that,

“Adherence to a dominant narrative ...may lead to oversimplification, stasis, and irreconcilable discrepancies between the story one has inculcated and one’s encounters in the world.” (Ochs and Capps, 1996: 32)

The “irreconcilable differences” they refer to is an apt characterization of the relationship between the dominant discursive form in my data – that is, narratives of self-transformation – and the discourse of a small minority of interviewees in my sample. In diametric opposition to the themes of empowerment and HIV as a catalyst for life change, these individuals describe the influence of their HIV status on their lives and self-concepts as devastating on both an emotional and a social level. In short, they articulate what might be termed “anti-transformation” narratives. Their narratives are dominated by themes of resignation, bitterness, fear and even despair, as interviewees focus on the great losses and hardships they have endured as a result of living with the virus – experiences that range from social stigmatization to an ever-present awareness of their own mortality. The discourse of these interviewees (seven, to be precise) points to one of the most troubling aspects of the dominant discourse of AIDS and, correspondingly, one of the most significant limitations of narratives of self-transformation, namely, a tendency to discourage the free expression of pain and suffering that is often a part of daily life with HIV or AIDS – pain and suffering that, as the discourse of interviewees who do not articulate narratives of self-transformation presented in this section makes clear, can be acute and unrelenting.

In its insistence on the vital importance of a “positive attitude”, the normative model of HIVer identity invites a denial of pain and suffering – particularly emotional pain and suffering – that may be experienced as a result of the stigma of an HIV or AIDS diagnosis, an intimate awareness of one’s own mortality, the contemplation of an uncertain future, or any of the other potential difficulties faced by those living with HIV or AIDS. As indicated by both interviewees’ discourse and my own participant-observation at GMHC and agency settings, the discussion of emotional pain, as compared to physical pain, is particularly taboo; this kind of pain is more threatening to the dominant interpretive perspectives of “empowerment” and “HIV as a catalyst for self-transformation” that agencies propagate and upon which many clients have in fact invested their sense of self. Therefore, the articulation of an effective and persuasive narrative of self-transformation requires either a suppression of painful experience or the provision of an appropriate justification for it. As a result, less sanguine attitudes or emotions are not given serious consideration within narratives of self-transformation; instead of being recognized as valid responses to a life-altering event or a troubled existence, they are dismissively relegated to the past, pathologized as symptoms of mental illness or social “isolation”, or identified with one’s pre-transformed identity, an identity that is frequently characterized as immoral.

Early on in her interview, Carla, a thirty-seven year old “stay-at-home mom” describes her attempt to come to terms with her HIV-positive status:

“...When this happened, I don’t know, I felt kind of cheated out of life. Like now I have to rush and do something for myself, enjoy life as much as possible, be around my kids as much as possible, make as much money as much as possible, make as much love as much – it’s like I had – it was a race against time.”
(Carla, heterosexual Latina woman)

The ambivalence in her discourse is clearly apparent as she tries to frame her own attitude towards life with HIV in a way that conforms to the normative model, but finds it a difficult fit. She indirectly references the dominant discourse’s emphasis on the necessity of maintaining a positive attitude by saying that after being diagnosed, she realized she had to “do something for myself, enjoy life as much as possible”, yet at the same time, she suggests that doing so has not come easily for her – while trying to “enjoy life as much as possible” she found herself in a “race against time”. Her discourse in this passage intimates the pain that lies just beneath the surface of her rather mechanical attempt to frame her experiences as a person living with AIDS in the terms of the dominant discourse. As the interview goes on, she voices this pain with greater candor, admitting, for instance, that she would like to get a job, but has been held back by her fear of becoming ill. As she explains it,

“...I’m kind of afraid, you know, to go back to work or to do any – ‘cause I have this fear that, what if – I always have this what-if hanging over my head, you know. What if I come down with something? What if your stomach starts acting up?”

Moreover, she feels that the fact that she is HIV positive has led her to “settle” for a romantic relationship she finds unsatisfying, saying, “I’m not really happy as far as my relationship is concerned because I’m kind of like I just settled for shit ‘cause I don’t expect more out of life.” Carla’s discourse hints at the pain that is unexpressed – and unexpressable – in the normative interpretive framework offered by narratives of self-transformation.

Another key thematic element of these “anti-transformation” narratives is that of HIV-related social stigma – in fact, social stigmatization is presented by all members of this subgroup as perhaps *the* defining experience of their lives as HIV-positive individuals. Carla says she has endured gossip, harassment and blatant discrimination as a result of her HIV status both from her neighbors as well as from the staff members and fellow parents at her son’s middle school where she had been volunteering; the harassment at the school became so severe that she was ultimately forced to transfer her son to a parochial school which she struggles to pay for with her disability income.

Reflecting similar themes, Howard and Earl, both of whom are residents of Solutionz, an SRO-style shelter in the Bedford-Stuyvesant section of Brooklyn that provides social services to homeless HIVers with histories of drug addiction, speak with great feeling about the emotional devastation that has resulted from their HIV-positive status and its associated problems. It should be noted that the lives of both of these men are fraught with difficulties in a number of arenas – from poverty and homelessness to drug use and

criminal history; however, what is critical to emphasize is the fact that they explicitly, and repeatedly, cite their HIV status as the prime cause of their unhappiness. While it is impossible for me to evaluate the substance of this claim, what I do see as significant is their use of HIV as a narrative pivot around which the other painful events in their lives revolve. In this manner, the structure of their life stories parallels narratives of self-transformation, except that what many other interviewees construct as a catalyst for newfound meaning and purpose in their lives, these men describe as nothing more than a wellspring of pain.

Howard, a forty-one year old man who was diagnosed with HIV seven years ago while in prison, describes the impact of HIV on his psyche in these words:

“[L]iving with HIV...consumes a lot of your thinking, you know. Uh with me, uh I don't feel as clean as I did before...it puts a lot of limitations on a person, you know. I don't, I don't feel comfortable going out like I used to, you know, like going to parties, clubs and bars...the question of death is always an issue...And for a person who isn't accustomed to, you know, thinking of death all the time that's very uh time-consuming. Unpleasant, you know? Death is a reality with those who are HIV-positive, especially who have been classified as AIDS, you know, and I'm classified as having AIDS...”(Howard, heterosexual African-American man)

His blatant admission of his fear of death is in direct conflict with the dominant discourse's truism that “AIDS is not a death sentence.” Despite such thematic departures, however, it is important to note that Howard's self-concept as an HIVer is hardly unaffected by the ideological tenets of the dominant discourse. Most saliently, he

shares the same moral framework upon which narratives of self-transformation are based, attributing his HIV status to his prior “immoral” lifestyle. As he describes it,

“...Before I was released from prison, I had reached the conclusion in my thinking that uh the possibilities of me contracting AIDS through the lifestyle I lived was very high...I knew deep down inside, you know, it came from, came from my behavior, my way of life...”

While he refers to IV drug use, pimping and having sex with prostitutes as specific components of this “lifestyle”, it is the global “lifestyle” more than any particular “risky” behaviors that he constructs as the ultimate “culprit”, as he puts it.

Like Howard, Earl has been emotionally devastated by his HIV diagnosis and by daily life with the virus. In addition, he is still grieving the loss of his wife and young daughter to the disease and has severe clinical depression that he feels is the result of living with AIDS. Since his diagnosis, he has made two suicide attempts, the first when he tested positive four years ago and the second one year prior to his interview –in response to his family’s rejection of him due to their prejudice and fear about AIDS. Despite all this trauma, he says he has recently made efforts to “turn his life around” in manner reminiscent of the signal themes of narratives of self-transformation. For example, after first “denying” the reality of his HIV diagnosis and continuing to use crack in the years immediately following his release from prison (where he initially learned of his HIV status), he recently stopped all drug use when his doctor told him he was killing himself. He also reports making attempts to eat better and to live a “healthier life”, although he acknowledges that this is extremely difficult to do in his present living conditions.

Because of his new conscientiousness towards his physical health, his viral load recently dropped to “undetectable” – an overt symbol of his success.

However, unlike most interviewees who have made similar changes, he does not present these events according to the typical plot structure of self-transformation narratives in which an acknowledgement of the reality of one’s HIV status, however delayed, propels a rebirth of the whole person. Within narratives of self-transformation, the reconstruction of a “healthy” and morally upstanding identity from a prior state of dissolution is typically accompanied by a reinvigorated emotional state as the HIVer establishes, for example, new social connections within an agency setting. In contrast to this, Earl, in a manner quite similar to Howard, presents his HIV diagnosis as having augured in a relatively constant state of internal chaos and wrenching unhappiness; the profound alienation from others, especially his family of origin, that he experiences as a result of the stigma that still surrounds HIV and AIDS cannot be lessened by agency affiliation or new associations with fellow HIVers. Although he attends numerous support group meetings, he says,

“I’m still not coping with this virus. I’m still not coping with death, with the, with the virus inside. Why me? Why I have to get it? Why I got to live with this? I shouldn’t have to live with it. But I do, and that’s something I have to, something I have to deal with all my life until my time comes.
(Earl, heterosexual African-American man)

Since the perspectives expressed in this subset of interviewees are not easily reconciled with the resolutely optimistic notions of “empowerment”, “positive thinking” and “doing for oneself” upon which the dominant discourse’s normative model of HIVer identity rests, they are routinely suppressed. Likewise, they cannot be given adequate voice within narratives of self-transformation; to the extent they are expressed at all in these narratives, they are either de-emphasized or relegated to the past, as exemplars of narrators’ “bad past selves”. This accords with Ochs and Capps’ discussion of the negative effects of dominant cultural narratives. As they note, the “silencing of alternative stories is a form of linguistic oppression. Dominating stories that preserve the status quo can estrange and muffle alternative perspectives.”(1996: 32). However, Ochs and Capps’ evaluation of the possible effects of the use of such “counternarratives” is more optimistic than my data would appear to suggest. It is their claim that such counternarratives, even those which, like the “anti-transformation narratives” articulated by these interviewees, do not “involve overt reference to a prevailing narrative world view,” may function as “acts of resistance”. In their estimation, “the voicing of a disjunctive reality ” involved in “the posing of an alternative account may be more effective in dismantling the status quo than overt critiques”, since the mere referencing of a dominant account serves to reproduce it (1996:36-37). While this may be the case in certain circumstances, there is no evidence to support such a sanguine interpretation with regard to the voices of the HIVers presented above.

To the contrary, these voices appear to have little, if any, effect on either the dominant discourse of AIDS or a broader cultural climate that presents the pursuit of self-fulfillment as a moral obligation. The philosopher Carl Elliott likens this quintessentially American notion that life is a “project”, the central goal of which is self-realization, to a “tyranny of happiness”; “whoever is unhappy is suspect.” (Elliott, 2003: 303). From this vantage point, narratives of self-transformation and the dominant ideology upon which they are based do more than deny these voices; they implicitly condemn them.

The “Life Cycle” of Narratives of Self-Transformation

An essential issue to consider with regard to narratives of self-transformation is the extent to which the changes they express are enduring. Are the identities HIV positive individuals construct in these narratives, and the affective, social and other benefits that they confer, lasting or transient? Even if one were to accept their beneficial effects at face value, the “longevity” of the new self-concepts and life stories they produce remains unknown. Although this issue is not directly addressed by any interviewee in my sample, including narrators and non-narrators alike, there is reason to believe that the self-transformations interviewees relate are more properly thought of as phases rather than permanent states of being.

This assertion is consistent with theoretical perspectives on identity construction both within the discipline of anthropology and in the social and behavioral sciences more generally which support a conceptualization of identity as shifting, fluid and contextually variable, adaptable to local constraints, goals and imperatives. (cf. Kondo, 1990; Kroskrity in Duranti, ed, 2001; Meacham, 2001). Moreover, it is supported by the following evidence in my data.

A notable commonality among the narratives of diverse interviewees is the relative recentness of both their self-transformations, as well as their agency involvement, two phenomena which are typically presented as temporally coincident. In fact, the vast

majority of narrators describe transformations that are quite “new”²²; on average, the “life turnarounds” of which they speak occurred approximately two years prior to their interviews. Included in this category are some of the most enthusiastic and highly involved agency clients, such as Arlene, Evette, and John, who articulate some of the most developed narratives of self-transformation. Correspondingly, there is a dearth of narrators evincing long-term transformations and agency involvement; the two notable exceptions are Thomas and Ron, who have been involved in volunteer and advocacy work for PWAC and other organizations for ten or more years. The pervasive “newness” of narrators’ self-transformations suggests that clients’ exemplary new identities, attitudes and behaviors, along with the heavy involvement in ASO activities that so frequently accompanies these changes, may not be sustainable. Instead, a certain transient quality appears to be inherent in the nature of the transformed identity itself.

²² To clarify this point, it may be useful first to distinguish between the two rather distinct senses of the term “new” I use, in different contexts, to describe narrators’ transformed identities. In one sense of the term, these transformed identities represent interviewees’ “new” selves in that they have replaced or succeeded their prior identities. From this perspective, “newness” is a function of sequential order alone; regardless of when the actual process of transformation occurred, the identity can be considered “new” until, hypothetically, another process of change were to occur, producing a still newer iteration of the self to replace it. According to the second sense of the term, the sense to which I refer above, “newness” references chronological time and is measured, in the present context, in months or years. Second, while any attempt to establish a specific length of time distinguishing “new” from “long-term” transformations is, of course, arbitrary, it should be noted that the self-transformations interviewees narrate cluster in two rather distinct groups with regard to their “age”. The majority of narrators present their transformations as beginning about two to three months to three to four years prior to their interviews; for heuristic purposes, I classify these as “new”. In contrast, as indicated above, two clients present exceptionally “long-standing” transformations which occurred ten or more years prior to their interviews.

As to the reasons for this apparent transience, several possibilities present themselves.

First, is this simply due to the quotidian exigencies of life, especially life with HIV?

Do clients cease to maintain their agency involvement, interest in learning about the disease and other correlates of a transformed identity because they become preoccupied by the day-to-day hassles of child care, managing their medical care, maintaining their medical coverage and/or benefits and so forth? As the examples related below suggest, while such circumstances may certainly be contributing factors, they do not appear to engender the phenomenon itself.

Another possibility, one which is clearly relevant to the situation of Bruce detailed below, is that certain individuals “burn out” on heavy agency involvement and the maintenance of the requisite positive attitude, finding themselves unable to sustain the emotional, mental and physical exertions necessary to maintain this transformed identity.

Although no interviewees in my sample highlight the state of their physical health as a significant reason for avoiding or discontinuing participation in agency activities, this must be considered as a potential factor limiting the amount of time narrators may be able or willing to commit to the agency activities that so frequently function as a catalyst for narrators’ transformations. In addition to the often tenuous nature of HIVers’ health, particularly for those with “old AIDS” (*POZ*, Sept., 2001: 36), another health-related factor that may complicate narrators’ ability to make long-term commitments to agency-based activities is the typically labile nature of HIV illness itself, an especially frustrating

feature of the disease for many interviewees who speak of feeling well enough to function normally for a period of time, until suddenly, they develop an infection or another complication of HIV that grounds them for weeks or months at a time. It is possible that this sense of uncertainty surrounding one's health may dissuade certain individuals from initiating volunteer work or committing to peer positions in the first place; alternatively, an unexpected illness or hospitalization may deflate an HIVer's motivation to follow through on such commitments once begun, or make doing so physically difficult, if not impossible. Nonetheless, it is equally important to point out that long-term transformations are not necessarily "unsustainable", even for those who have experienced significant and repeated health-related setbacks. For example, consider the long-term survivors Thomas and Ron. They are the two narrators with the longest continuous agency involvement and "oldest" transformed identities. Significantly, they are also "long-term" survivors of AIDS in the medical sense and are among those sample members who have been living with HIV for the longest time. To be specific, Thomas was diagnosed with AIDS-related symptoms in 1981, before the syndrome was even named, and Ron officially tested positive in 1985, shortly after the Elisa antibody test became available, although he believes he had already been infected for several years at that point. While Thomas has remained fairly healthy throughout the years since his diagnosis and may in fact be a "long-term non-progressor"²³, Ron has been extremely ill,

²³ The Encyclopedia of AIDS defines both "long-term survivors" and "long-term non-progressors" as "individuals with HIV whose disease progression has been slow or minimal." The term "long-term non-progressor" specifically refers to "asymptomatic HIV-positive people whose immune status, especially their CD4+ cell count, remains in the normal range"-i.e., they do not progress to full-blown AIDS for significantly longer than the mean of "10 to 12 years" after seroconversion. (Remein and Ho in Raymond Smith, ed., Encyclopedia of AIDS. 2001: 428-429)

even near death, on a number of occasions, and at the time of his interview was recovering from a three-year bout with lymphoma from which he initially believed he would not survive. Notably, both of these men have maintained their active participation in AIDS advocacy work, manning the phones for PWAC's "peer-run" AIDS hotline and volunteering for other AIDS organizations, for over ten years.

However, even in Thomas's and Ron's discourse, there are none too subtle hints of unwelcome change in the institutional climate around them, as the particular agency – PWAC – in which they had invested so much of their advocacy work and their sense of identity as "people with AIDS" was in the process of folding at the time of their interviews in the summer of 1999. This points to another reason why narrators' transformations may not last – namely, because the institutional context of AIDS services is continually shifting, for reasons that include: epidemiologic shifts in the epidemic and corresponding changes in agency clientele and changes in funding patterns that in recent years have led to a constriction of budgets and services at large ASOs such as GMHC.

Additional support for my claim that the self-transformations articulated by interviewees are more appropriately conceptualized as phases as opposed to permanent states is provided by the discourse of two interviewees in my sample, Julian and Bruce.

A comparison of these two men's descriptions of the impact of HIV on their lives supports the notion that HIVers' self-transformations themselves, along with their narrativizations, which at once represent and constitute the changes they relate, can be

understood as existing on a continuum. In fact, a juxtaposition of the discourse of Julian and Bruce, both of whom are gay white men, suggests that there is a typical a “life cycle” of self-transformations according to which they start strong, typically when an individual first initiates serious agency involvement, but may peter out over time. At the time of their interviews, Julian and Bruce appear to be at the opposite ends of this life cycle; Julian is just commencing his life change, while Bruce is in the later stages of a transformation begun several years earlier.

Julian, a thirty-nine year old gay white man who was diagnosed with “full-blown” AIDS in 1990 and has been living on private disability for the past five years, illustrates what is apparently an “incipient” narrative of self-transformation, presenting himself as in the early stages of a characteristic transformative process. In recent months he has been increasingly conscious of his physical and mental health, initiating behavioral changes that include: “eating like a normal person” in order to keep up his weight; consistently engaging in “safer” sexual practices; cutting down his recreational drug use; and making an effort to get out of the house each day, lest he be tempted to lie on the couch all day smoking pot.

When asked, “So do you think it’s [living with HIV] had an impact on you like over, over the years, the ten years since you’ve known? Have you changed like aspects of your life because of it or anything?” he says:

“Yeah. I mean, last, the last year more than anything. Um I don’t go out very much. Um and I’ve always been a real heavy party boy, you know. Um go out to the big clubs, big parties, never missed a big party. Always had a couple different flavors of something in my pocket and um uh I’ve been a real big pothead, which I’ve pretty much stopped. Um recently, like in the last six [weeks]...I was smoking cigarettes heavily, two packs a day, and I quit six, seven weeks ago, you know, cold turkey.” (Julian, gay white male)

A bit later in the interview, he reprises his discussion of his efforts to stop using “recreational drugs”, explicitly emphasizing the newness of these changes, as he contrasts his old self, “back then”, with his emerging new self:

“...it just kicked in recently”, he says, “Back then, it was like I’m not going to let it change my life. Um I think a went to [a nightclub]. I did my hit of Ecstasy, yeah. Um, this is a new thing. I want to get rid of, I want to get over all these recreational drugs ‘cause I’ve always done a lot of recreational drugs.”

A particularly striking feature of his description of his recent lifestyle changes is the extent to which portrays himself as in the midst of a process of conscious change in which he is attempting to adopt normative standards of behavior. In the following passage, he evaluates his attempts at change, implicitly orienting to dominant behavioral norms, by, for example, rating his own progress as “good”, but “not great”. In reference to his eating habits and other health-related behaviors, he says:

“Lately I’ve been pretty *good*. I feel like I’m like *trying to go through a change* and start taking care of myself, where I know I’m really my own worst enemy as far as the way I take care of myself, which is *not great*.” Um, I don’t take vitamins or anything like that. Um, I figure, you know, I take enough pills, I really don’t want to add a handful of vitamins to it. Um but you know, I make sure I eat breakfast. Now I’m on Norvir, I must eat when I take Norvir, I must, otherwise I feel horrible. So, you know, I get up, I wake up at the crack of dawn. I’m out of bed and out of the house by six-thirty in the morning, um.” (italics added)

Another significant aspect of this passage for the present discussion is the way Julian presents himself as, in effect, halfway there; while he is aware that he has not yet attained total success, he notes that he has made progress in specific areas. This is demonstrated by the alternating quality of his self-assessment in which his initial positive evaluation – *“Lately I’ve been pretty good. I feel like I’m like trying to go through a change and start taking care of myself”* – is followed by an admission of weakness – *“I know I’m really my own worst enemy as far as the way I take care of myself, which is not great”* and a supporting example – *“I don’t take vitamins or anything like that.”* This is in turn followed by both a rationalization of the problematic behavior – *“I figure...I take enough pills, I really don’t want to add a handful of vitamins to it.”* – and two examples of positive changes he has made, eating breakfast every day and rising early every morning. Significantly, he ends his turn on this upbeat note which has the effect of lending greater weight to the positive changes he has made than to his remaining weaknesses.

Incidentally, Julian’s discourse also bolsters my assertion that HIVers’ transformations are intimately associated with agency affiliation, as he presents his incipient self-transformation as contemporaneous with his first serious effort to access agency services – specifically, a GMHC support group – and to follow through on this commitment. Although he has known of his HIV status for ten years, his prior experience with AIDS services has been extremely limited, consisting of only a single Body Positive group meeting nine years earlier.

In contrast, Bruce's self-presentation stands as an example of the other end of the "life history" of a self-transformation narrative; he relates a narrative of a transformation that is burnt out, past its prime and has lost its usefulness. In the interview segment presented below, he speaks of the disillusionment with life his HIV diagnosis has visited upon him. When asked "Do you think that on the whole, being diagnosed has affected how you think about yourself and your life?", he responds:

B: “Oh yeah, it definitely, you know, took the color out of the picture for me in a lot of ways. I mean... the hope of the future, you know. I didn’t dream that... I would be... alive this long, you know, but even, even at that time, I think it really took a lot of the the zest and vibrancy out of life for me. I was depressed a lot of the time, um I didn’t, you know, I didn’t really think in terms of um uh a career, you know, ‘cause I didn’t think I was going to be able to establish myself uh work-wise, and it was just kind of like that time bomb being ready to drop any minute, you know, it was like when’s the next step? When am I gonna, you know, move on to, you know, to the AIDS thing? And uh, and then the loss of many friends, at that time too, it was kind of uh uh all that multiple grief, I think, was very, a tumultuous period.

I: And do you think that your feelings have changed over time?

B: No. I think I’ve learned to live with myself as I am. Um I think that now there’s a lot more treatment, so you know, yeah, we’re all living longer, but yeah, I’m not so sure if that’s really a good thing either because sometimes it’s like between the rock and the rock, you know. It’s not uh—there’s no solution, um you know, for all intents and purposes.”

Throughout his interview, he is starkly honest about the tremendous losses he has experienced as a result of HIV, as well as his realization that his life will never be what it might have been had he not been infected with HIV, that he will never be able to reach the state of “acceptance” of his HIV status that he once aspired to. In its bleakness his discourse rivals that of Howard and Earl, the two clients of Solutionz whose depictions of their self-images, outlooks on life with HIV and presentiments of their own futures I characterized as “anti-transformation narratives”.

However, Bruce’s discourse presents a narrative distinction that is highly significant; with his prior heavy agency involvement in multiple roles from client to committed volunteer, and his immersion in self-help ideology that was popular in the AIDS world in

the late 1980's and early 1990's (such as Louise Hays' writings on death and dying, "AIDS, Medicine and Miracles" workshops), Bruce seems to have undergone the kind of self-transformation other interviewees narrate. However, unlike theirs, his transformation occurred a number of years ago and now he presents himself as disillusioned, depressed and disappointed – exhausted, really, by the difficulties of living with the virus for so many years, as well as witnessing the wide swath of death created by AIDS in his circle of friends and acquaintances on the West coast. It is important to note, however, that despite his feelings, he remains involved in the AIDS service system since his recent move back to New York City two years prior to our interview – specifically, he is a peer health educator at GMHC and a client there.

Bruce's interpretive perspective suggests a potential problem with the transient nature of narrators' self-transformations; as illustrated earlier, part of the cost of adopting a transformed identity is the denial of one's past that it requires, at least to a certain degree, for all narrators. In the extreme, what might be the consequences for an individual who denies and derogates his prior identity, divorcing himself from his own history in order to adopt a new self-image which ultimately proves to be transitory, unsustainable or unfulfilling?

Social Patterns in the Use of Narratives of Self-Transformation

The central objective of this section is to ascertain which HIVers are most likely to use narratives of self-transformation and, then, by inference, to speculate as to which HIVers may not be represented among these narrators. For example, does the self-transformation construct just work for a minority of especially motivated, optimistic HIVers? Are the voices and perspectives of particular HIVers systematically absent from the discourse of renewal and empowerment presented in the previous chapter? Is the mode of identity construction offered by narratives of self-transformation less available to certain HIVers? If so, what are the probable reasons for this disparity, and what might be the real-world implications of this bias?

In order to address these questions, it is first necessary to briefly acknowledge the most likely sources of sampling bias vis-à-vis my overall sample of interviewees and the implications of this selective representation for my interpretation of narratives of self-transformation. The issue of sampling bias is relevant to my larger objective of determining social patterns in the use of narratives of self-transformation since systematic biases within the larger sample are necessarily transferred to any subset of this sample.

Interviewees as “Survivors”

The interviewees in my sample, and therefore, the subgroup of narrators as well, necessarily represent the voices of “survivors”. To a significant extent they are those individuals who have “survived” HIV infection in multiple senses of the term - physically, emotionally, socially and spiritually. On the whole, with only a few exceptions, the individuals I interviewed were in good physical and mental health at the time of their interviews – a fact that cannot be claimed with regard to all members of the population of HIV positive individuals in New York City. In addition to living well with HIV on a physical level, sample members represent those HIVers who have generally been able to successfully manage their lives with HIV and, more often than not, to overcome the various problems that are associated with HIV infection in U.S. today - from the myriad physical problems that are caused by the virus itself or by toxic side effects of antiviral medication, to the frequently co-existing social problems of poverty and drug addiction that are endemic in many communities “hardest-hit” by HIV and AIDS, to the decimation of community and friendship networks by AIDS that has, for some individuals, created an experience of protracted grief. In short, then, my sample of interviewees is biased towards physically healthy and relatively high-functioning HIVers. With regard to the subgroup of interviewees who use narratives of self-transformation, these trends are even more pronounced.

Agency Affiliation

Perhaps the most salient feature distinguishing study participants is their affiliation with AIDS service organizations – a feature that is a direct result of my recruiting strategies²⁴.

All interviewees included in my sample were clients of at least one AIDS-related service organization at the time of their interviews, the vast majority as clients of GMHC.

Furthermore, as has been noted previously, many interviewees were clients of multiple AIDS service or advocacy agencies and/or participated in these organizations in multiple roles in addition to that of “client”, working, for example, as hotline volunteers, peer educators or peer outreach counselors. Thus, to a significant extent, this sample consists of a fairly select group of HIVers.

Most obviously, this sample is comprised of those HIVers who, at the time of their interviews, are “in the system”, availing themselves of services and benefits and not living on the street, using drugs and/or going without medical treatment, as several interviewees were at prior times in their lives. Further, as active members of an ASO, most of whom regularly participate in on-site agency activities, they are, by definition,

²⁴ See Chapter 2 for a more detailed discussion of my recruiting strategies. For the purpose of the present discussion, it suffices to say that all interviewees included in the present “sample” were recruited through the AIDS service organization context, whether directly or indirectly. The majority responded to flyers advertising my study that were posted in various locations at GMHC, while a small minority were referred to me through friends of theirs who were GMHC clients and had seen my flyer. However, all sample members, regardless of how they learned of my study, were clients of at least one AIDS-related service organization at the time of their interviews.

physically and emotionally well enough to engage in these activities. Indeed, such an agency-derived sample is unlikely to include, and in fact does not include, individuals who are currently extremely ill with advanced AIDS or are housebound due to illness. Likewise, only one individual in the sample appears to be experiencing serious mental illness at the time of the interview (Earl, one of the clients of Solutionz, who is clearly suffering from serious depression). Therefore, it can be reasonably hypothesized that this subset of HIVers is healthier, both physically and mentally, than is typical of the entire population of HIV positive individuals in New York City. Extrapolating from this hypothesis, it would appear as though this tendency is even more true of narrators of self-transformation stories who tend strongly to be the most active and heavily-involved agency clients within the sample.

HIVers who are active participants in service organizations are also those who, at least to a certain extent, “believe in” the service ideology of ASOs. Thus, one would not expect HIVers with radically anti-institutional or anti-ASO points of view to be represented in this sample – for example, resolute individualists who resist group affiliation altogether, individuals who resist affiliation with AIDS-related organizations in particular, or those who feel uncomfortable receiving help from social service organizations in general. In particular, interviewees who articulate narratives of self-transformation are those who have “bought into” the dominant ideology of the AIDS establishment, inasmuch as they have accepted the dominant discourse’s model of “proper HIVer” identity and have adapted their subjectivities and life stories to it.

As to why the most-involved agency clients are also the most likely to adopt and internalize agency ideology, one component of this dynamic is that heavy involvement in agency activities implies greater exposure to agency-promoted ideology, as opportunities for receiving and participating in multiple forms of agency-sponsored discourse increase with participation. Yet this is only part of the equation, for mere exposure to ideology is not sufficient; clients for whom agency affiliation is a central and meaningful part of their lives and identities are also likely to be more invested in agency-propounded, officially-espoused ideologies since they derive more of their sense of self-worth from agency participation and the fulfillment of agency roles. As a result, their identities come to center on both their HIV-positive status and the ideology of the institution.

As a final point, I note that while it is true that only certain individuals pursue and find fulfillment in agency involvement, clients' testimony suggests this is not strictly determined by variables of social identity such as race, class, gender or sexual orientation. As has been demonstrated, some of the most involved clients in sample, including Arlene, Evette and Thomas, are people of color – particularly, although not exclusively, women – from low-income backgrounds who have little if any formal work history, and frequently have histories of long-term drug dependence and/or involvement with the criminal justice system. Indeed, as noted in the previous chapter, the success these individuals have achieved within agency context is so meaningful and cherished precisely because they feel that prior to their HIV diagnosis they had achieved little if any

material or employment-related success in their lives and lacked opportunities to attain positions of social status. Since their agency involvement has afforded them some measure of such opportunity, their success within this institutional context serves to reinforce their ideological investment, creating a mutually reinforcing dynamic.

“Innocent Victims”: The Rhetoric of Blame as a Strategy for Moral Rehabilitation

To present a counterpoint to narratives of self-transformation, an alternative strategy for moral recuperation in the face of HIV is represented by the discourse of blame and the associated trope of the “innocent victim”. As Adam and Sears point out, the availability of this strategy for countering the stigma of HIV in order to construct a ‘moral’ identity as an “HIV positive” person is highly selective (Adam and Sears, 1996: 71). To frame the issue in Goffman’s logic and terminology, the use of this strategy is restricted to society’s “normals”, namely, those individuals whose pre-HIV identities are considered “ordinary” or “natural”, free of the “discreditable” attributes of homosexuality or drug addiction which render a subject already guilty in the eyes of mainstream society (Goffman, 1963: 5 and 2). In keeping with this logic, those individuals who have taken refuge in the “innocent victim” construct in mainstream American AIDS discourse over the last 20 years have historically tended to be hemophiliacs or self-professed non-promiscuous heterosexuals, especially women, who have typically presented themselves as passive objects of a malicious infecting agent, for example, as faithful wives or girlfriends duped by a philandering or IV drug-using male partner.

These stereotypical representations are replicated in my data by a minority of interviewees. As mentioned in the previous chapter, one salient factor distinguishing my overall sample of interviewees from the subgroup of narrators is the absence of heterosexual women who were infected with HIV by their male drug-using sexual

partners from the group of individuals who use narratives of self-transformation. And in fact, most of these women do make some use of this rhetoric of blame.

For example, in stark contrast to the emotional tenor of narratives of self-transformation, the discourse of Tina, a forty-four year old mother of four children, is characterized by anger and resentment, as she speaks bitterly of her now-deceased IV-drug-using husband who infected her with HIV eleven years earlier. In the following passage, she describes her feelings towards her husband after they both tested positive in the late 1980's:

“I was very, very angry at him. Very – I was angry that he infected me, but I was angry because of my children, ‘cause they would have to pay because he would die and I figured eventually I was going to die, and these kids were going to be without any parents... That was like the last straw. It was twenty-two years of hell with him, but finding that out, it was like that’s it, you know?... And then I watched him, while I watched him deteriorate, I just used to say, look at what you’ve done, you know?” (Tina, white, heterosexual woman)

Throughout her interview, she presents her late husband as a morally suspect individual – not only did he threaten the well-being and the very survival of their entire family by introducing HIV into its midst, he is morally culpable simply by virtue of his identity as a drug addict. The implication of her rhetoric of blame is that there are “deserving” and “undeserving” “victims” of HIV; while her husband is “deserving” of HIV as a result of his immoral conduct, she, by contrast, is an “innocent” and unsuspecting “victim” of his moral treachery.

An important point to note with regard to both of the alternative discursive forms discussed in this chapter – “anti-transformation” discourse and a rhetoric of blame that positions a subject as an “innocent victim” – is that they are not mutually exclusive; interviewees who do not use narratives of self-transformation can – and often do – rely on multiple discursive forms and strategies in their interview speech. For example, Tina and Carla both articulate strongly negative assessments of the impact of HIV on their lives that I likened to “anti-transformation” discourse, while, as the previous examples have shown, they also position themselves as “innocent victims” of their IV drug-using former husbands.

In contrast to the above examples, no narrators of self-transformation stories position themselves as “innocent victims”, casting blame for their HIV status on particular individuals who infected them with malign intent or willful, reckless disregard for their well-being. On those relatively few occasions when narrators do identify a particular individual as a likely source of infection, they do so carefully, noting that their hypotheses are unconfirmed, and without rancor, placing ultimate responsibility for their infections upon themselves. In so doing, they display yet another aspect of their transformed identities – their emotional honesty and moral rectitude.

Conclusion

A central claim of this work has been that institutions of the “AIDS system”, including AIDS service organizations, play a critical role in advancing the ideology of the dominant discourse of AIDS inasmuch as they encourage clients to construct particular subjectivities as “people living with HIV or AIDS” that are in conformity with the ideological tenets of the dominant discourse. More specifically, ASOs such as GMHC encourage clients to construct their lives and identities as HIVers according to the trope of self-transformation; they also shape HIVers’ identity constructions by producing and promulgating discursive forms – both interactional and textual – that convey a normative model of “proper” HIVer behaviors and interpretive perspectives. An examination of HIV positive interviewees’ narratives of self-transformation has suggested that many clients adopt and internalize, at least to a certain extent, these dominant ideologies of the “AIDS system”. Furthermore, this “AIDS system” ideology is connected to, and may be understood as a specialized version of, a wider ethos of American culture – namely, a belief in the endless possibility of self-reinvention.

From a theoretical point of view, this analysis may serve as an example of how a contextually specific hegemonic order sustains itself. The “AIDS system” provides a useful case study of these processes in action, as it is a fairly delimited institutional complex in which a fundamental and mutually-reinforcing ideology is shared among multiple institutional sites. From this perspective, then, it appears as though “mega-

ASOs” such as GMHC are, at this particular juncture in the history of the AIDS epidemic in the U.S., functioning as conservative social forces within the “AIDS System”, functioning to reproduce the dominant ideology and thus maintain the status quo.

This is significant for several reasons. First, it wasn’t always so. Although GMHC has, throughout its history, been criticized for its allegedly passive political stance, the agency did begin its life as a truly grassroots organization. Second, GMHC is, by many accounts – from my own experiences there, to the testimony of interviewees which was generally quite positive in regard to the organization, to the experiences of friends of mine who receive free acupuncture, massage and yoga classes there and rave about it – a “quality” organization, especially in comparison with many of the alternative social services available to HIVers. A final point of significance lies in the implications of this particular organization’s historical evolution for social movements generally. For example, Stoller (1998) points to processes of “bureaucratization” and “professionalization” as trends within the “AIDS system” as a whole; a companion piece to this trend is the demise, or foundering existence, of more radical groups such as ACT-UP. Looking beyond the arena of HIV/AIDS, what does this imply with regard to social movements generally? Is “radicalism” itself a phase, inherently unsustainable?

With regard to larger the implications of this analysis, one salient effect of the dominant AIDS discourse is to reproduce and further legitimize hegemonic medical constructs. Meanings produced about HIV/AIDS within the medical arena are adopted, reproduced

and disseminated within other, non-medical settings of the “AIDS system”, particularly within the AIDS service organization setting and in texts of HIVer literature. Thus, meanings produced in one arena are distributed throughout the entire system.

-This reproduction of medical knowledge is not straightforward “copying”. Instead, there are multiple processes by which medical knowledge is reproduced, some more faithful to the original than others. For example, “official” discourse of the ASO may attempt to be faithful to an original source, presenting itself as merely conveying medical and scientific findings to clients, but this necessarily entails processes of translation and interpretation as complex technical knowledge that is typically produced in a specialized, technical register is simplified for a general audience; various ideological transformations may be a part of this process. Another process by which medical knowledge is reproduced involves the application of medical concepts, terms and categories to new phenomena in a kind of “metaphorical extension”, as my analysis of the way in which an “undetectable” viral load is used by HIVers’ as a badge of achievement. The ultimate effect of this systemic distribution of medical knowledge is to facilitate the hegemony of medical claims to “truth”. As medical knowledge spreads throughout the system of institutions and is generalized, it becomes a template for other forms of social knowledge.

In my Master’s thesis, I argued that mainstream media, along with some governmental texts on AIDS, constituted a hegemonic AIDS discourse, while various forms of HIVer-centered discourse, including texts produced by GMHC and literature of the “PWA

Empowerment Movement”, articulated ideological positions that were fundamentally oppositional to these hegemonic texts, thus constituting “counter-hegemonic” discourse. However, in the present work, I have argued a rather different position, considering all of the texts cited above to be manifestations of a dominant discourse of the AIDS system. Thus, the dominant discourse in the present analysis includes both mainstream media directed at a “general”, unspecified public, as well as texts produced by AIDS system institutions specifically for an HIV-positive audience. I believe this interpretive shift on my part reflects, at least in part, diachronic changes that have occurred within the field of AIDS discourse over the past eight years since I completed the earlier work. It is hardly surprising that AIDS discourse has evolved, since the cultural experience of the AIDS epidemic has changed so significantly from the mid-1990’s to today.

Appendix A:

List of Interviewees

Included in this list are the 34 HIV positive individuals who participated in one-on-one semi-structured interviews and are included in my “sample” of interviewees. All interviews were tape recorded and then transcribed. While not all of the 34 sample members are quoted in the text of my paper, all of these interviews have formed the basis of my overall analysis. Not included within this “sample” of interviewees are the four HIV positive individuals with whom I conducted initial “pilot interviews” in order to refine my list of questions. Those interviewees whom I recruited through GMHC and who were also active GMHC clients at the time of their interviews are listed as “GMHC clients”. For those interviewees who were referred to my study through “snowball sampling” (typically through a friend or acquaintance who was a GMHC client and had seen my flyer posted at the agency) and who were not GMHC clients at the time of their interviews, I have determined their “primary agency affiliation” from the content of their interview speech. Demographic variables were determined by interviewees’ self-report. All names have been changed to protect individuals’ confidentiality.

GMHC Clients

1. **Nancy**, 38 year old heterosexual white woman. Interviewed on 7/16/99.
2. **Arturo**, 33 year old Latino heterosexual Latino man. Interviewed on 7/16/99.
3. **Carla**, 37 year old heterosexual Latina female. Interviewed on 7/19/99.
4. **William**, 49 year old heterosexual Latino man. Interviewed on 7/22/99.
5. **Kelly**, 50 year old heterosexual white woman. Interviewed on 7/22/99.
6. **Sonia**, 37 year old heterosexual Latina woman. Interviewed on 7/23/99.
7. **Theresa**, 42 year old heterosexual Latina woman. Interviewed on 7/27/99.
8. **Anna**, 49 year old heterosexual white woman. Interviewed on 7/29/99.
9. **Roland**, 29 year old gay African-American man. Interviewed on 7/30/99.
10. **Ken**, 46 year old gay white man. Interviewed on 8/2/99.

11. **David**, 46 year old gay white man. Interviewed on 8/3/99.
12. **Ron**, 46 year old gay white man. Interviewed on 8/3/99.
13. **Gloria**, 55 year old heterosexual white woman. Interviewed on 8/4/99.
14. **Peter**, 34 year old gay Latino man. Interviewed on 8/4/99.
15. **Thomas**, 45 year old heterosexual African-American man. Interviewed on 8/10/99.
16. **Rosie**, 47 year old heterosexual Latina woman. Interviewed on 8/11/99.
17. **Valerie**, 38 year old heterosexual white woman. Interviewed on 8/11/99.
18. **Raul**, 55 year old gay Latino man. Interviewed on 8/12/99.
19. **Dan**, 50 year old bisexual white man. Interviewed on 8/12/99.
20. **Henry**, 31 year old gay African-American man. Interviewed on 8/13/99.
21. **John**, 53 year old gay white man. Interviewed on 8/13/99.
22. **Judd**, 40 year old gay white man. Interviewed on 8/17/99.
23. **Bruce**, 44 year old gay white man. Interviewed on 8/18/99.
24. **Mary**, 31 year old heterosexual white woman. Interviewed on 8/23/99.
25. **Arlene**, 46 year old bisexual African-American woman. Interviewed on 8/24/99.
26. **Julian**, 39 year old gay white man. Interviewed on 8/24/99.
27. **Buzz**, 47 year old gay white man. Interviewed on 9/21/99.
28. **Tina**, 44 year old heterosexual white woman. Interviewed on 9/21/99.
29. **Victor**, 51 year old gay white man. 11/3/99.

Clients of Other Agencies

30. **Wayne**, 38 year old, heterosexual African-American man. Interviewed on 8/10/99; client of Housing Works.
31. **Evette***, 47 year old bisexual African-American woman. Interviewed on 8/12/99; client of Exponents/Arrive.
*Evette and Edgar, who are romantically attached and living together, participated in a joint interview.
32. **Edgar***, 45 year old bisexual African-American man. Interviewed on 8/12/99; client of Exponents/Arrive.
*Evette and Edgar, who are romantically attached and living together, participated in a joint interview.
33. **Howard**, 41 year old heterosexual African-American man. Interviewed on 8/23/99; client of Solutionz.
34. **Earl**, 40 year old heterosexual African-American man. Interviewed on 8/23/99; client of Solutionz.

Appendix B:

Interview Schedule for Individual Interviews

General Information

1. Can you tell me a little bit about yourself or describe yourself to me?
2. Can you remember when you first heard about AIDS?
How about when it first became real to you, or 'hit home' for you?

Diagnosis

3. When did you first learn that you were HIV-positive?
What was that experience like for you?
How do you think you became infected?
4. Do you have an AIDS diagnosis?
If yes, what was this like for you?
5. Did getting an HIV or an AIDS diagnosis change how you felt about yourself or your life?
If yes: How so?
6. Have you changed aspects of your life because of your diagnosis?

Relationships

7. Who in your life knows about your HIV status?
8. How did you decide who to tell?
9. How did you go about telling people?
What was this process like for you?
10. Is there anybody you'd like to tell, but haven't?
If yes: Why haven't you disclosed to them?
- 11.a. Do you know other people with HIV?
- 11.b. *If yes*: Who?
How close are you to them?
Do you think this helps in living with HIV?

12. Do you think being HIV-positive has affected your relationships with people close to you?
If yes: How so?

Work

- 13.a. Are you working now?
 Why or Why not?
- 13.b. *If yes:* What's it like to manage being HIV-positive with working?
 Are your work activities different than they used to be?
 Do your co-workers know about your status?
 Do you think it would create problems for you if people at work knew?
 Have you faced discrimination at work because of your status?
- 13.c. *If no:* Did you stop working for health reasons?
 What's it like for you not to be working?
For those who stopped working for health reasons: Have you thought about returning to work?

Service/Advocacy Involvement

- 14.a. Are you involved in any HIV-related social services, things like support groups, drop-in programs and the like, or have you been in the past ? (*whether at GMHC or at other organizations*)
- 14.b. *If yes:* What kinds?
 Can you describe your involvement a bit?
 How important are these activities in your life?
- 14.c. *If no:* Why not?
- 15.a. Have you had problems getting the services or benefits you need?
 Or problems working with service organizations and/or benefit bureaucracies?
(e.g., problems with ASOs or SSI/SSD, DAS and/or unresolved housing, immigration issues, etc.)
- 15.b. *If yes:* Can you describe a significant problem as an example?
16. Have you been involved in any AIDS-related advocacy or volunteering work?
 Why or Why not?

Medical

- 17.a. What kind of medical treatment are you involved in now?
Are you on any HIV medications?
- 17.b. *If yes:* Which ones?
What's it like taking these medications?
- 17.c. *If no:* Why not?
18. Have you had any problems getting the medical care that you need, or getting coverage for medical care?
If yes: Could you explain?
19. Does your medical care affect your daily life?
If yes: How?
20. Were any treatment decisions hard for you?
If yes: In what way?
21. Do your current medical stats influence how you feel about yourself or your life in general?
If yes: How?
22. Are you satisfied with your medical care overall?
Why or why not?

Routines

23. What's a typical day like for you?
Is this different now since your diagnosis?
Why or why not?
24. What kinds of things help get you through the day, keep you going?
What things do you look forward to?

General

25. Do you think your outlook on life has changed from living with HIV?
If yes: How?
26. How about your goals in life, plans for the future?

27. What do you think about the idea of an “AIDS community”?

Is this concept meaningful to you?

If yes: What does it mean to you?

If no: Why not?

28. Is there anything you'd like to add to what we've been talking about?

Demographic Information

Age:

Gender:

Race/Ethnicity:

Sexual Orientation:

Country where you were born:

First Language:

How do you pay for medical care?

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